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THE ROLE OF TRUST IN THE PATIENT-
HEALTHCARE EXPERT REMOTE
COMMUNICATION: THE CASE OF GREEK
HEALTHCARE PRIVATE-PRACTITIONERS

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PHD 2017

THE ROLE OF TRUST IN THE PATIENT- HEALTHCARE EXPERT REMOTE COMMUNICATION: THE CASE OF GREEK HEALTHCARE PRIVATE-PRACTITIONERS

VASILEIOS KALYVIS

A thesis submitted in partial fulfilment of the
requirements of the Manchester Metropolitan
University for the degree of Doctor of
Philosophy

Department of Marketing, Retail and Tourism
Faculty of Business and Law
Manchester Metropolitan University

2017

Declaration

I declare that this Ph.D. thesis, entitled **“The role of trust in the patient-healthcare expert remote communication: the case of Greek healthcare private-practitioners”**, has been compiled by me under the supervision of the Professor Sue Baines (Director of Studies), Dr. Ghulam Nabi (supervisor) and Dr Catherine J. Ashworth (supervisor). No part of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or institution.

A handwritten signature in black ink, appearing to read 'V. Koly', is shown within a light gray rectangular box.

Signature

Abstract

Rapid developments in the field of information and communication technologies (ICT), in parallel with the steady coverage growth of mobile cellular networks, have shaped a digital meeting space for patients and healthcare experts. However, this space remains largely unexplored. There is a large body of telemedicine research, but it almost always reports technical pilots within institutional settings, overlooking the use of everyday technologies [designed for personal rather than medical communication] in the healthcare sector. Lack of knowledge about the role of trust in the context of remote communication via ICT between patients and healthcare experts reflects a significant research gap addressed in this thesis.

I use original, in-depth qualitative evidence to explore the role of trust in the context of ICT-enabled remote communication in healthcare. Sixteen private practitioners based in Greece took part in the research. They were specialised in the fields of physical and mental health. All used ICT to support remote communication with their patients.

The emerging theory developed within the framework of the current thesis demonstrates that, in the light of an identified *medical-data-gap* due to the limited *perceived affordances* of the ICT selected for computer-mediated communication (CMC), *patient's trustworthiness* matters. Physicians hesitate, or even refuse, to proceed with any medical act, such as diagnosis, medication regime, prescription or guidance, in a remote manner, to patients whom they do not trust, especially in terms of their communicational skills. However, it is being demonstrated that this applies only to physicians (meaning those who treat physical symptoms) and not to mental health experts. Finally, there is evidence that, for mental-health experts, the accessibility provided by ICT nurtures trust maintenance and trust development with their patients.

This doctoral thesis is innovative in that it sheds light on remote communication between healthcare experts and patients via everyday technologies, with a special focus on the element of trust. Moreover, it is innovative in that it borrows, for the first time, key-theoretical properties from the 'distant' discipline of CMC in order to explain patterns regarding healthcare experts' attitude towards ICTs.

Dedication

The current PhD thesis is specially dedicated to all individuals suffering from depression and instead of giving up, they give themselves every single day a chance of rising up.

Acknowledgements

Being a part-time PhD student living on a permanent basis outside the UK borders was not an easy task. During these years, I have been a father twice, we –as a family- changed three different houses while we handled serious health issues. Inevitably, I have been a part-time father and a part-time husband too. The implementation of the current research work wouldn't have been achieved without the understanding, patience and motivation provided by my family. So, this PhD thesis is dedicated to my beloved children Electra and Orestes and to my dear wife Eleni Theodoridou.

I am also grateful to my proof-readers Roula Demetriou and Kleo Webber for their consistency, commitment and effectiveness under stressful circumstances. Special thanks to my dearest friend Demis Kyriacou who used to remind me that I am a *human being* instead of a *human doing* and that no matter the examiners' decision, I am worthy.

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Yours Sincerely,

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Chapter 1

Introduction

1.1 Setting the scene

It is a fact that rapid developments in the field of information and communication technologies, (ICT) in parallel with the steady growth in coverage of mobile cellular networks, have both shaped a digital meeting space for patients and healthcare experts. This interactional space has now come either to supplement or even substitute traditional face-to-face sessions. As Palmieri and Stern (2009) mentioned “[...] information exchanges are increasingly electronic; fewer face-to-face interactions make communication even more challenging” (p. 163) in the contemporary medical scene. The increasing infusion of ICT into the health sector (WHO, 2016) has resulted in a shift of research interest from how to spread ICT in the health sector, to how to make the most out of the contemporary ICT for patients’ benefit (Andreassen and Skrovseth, 2016).

In more detail, a recent study implemented by the World Health Organisation (2016) demonstrated that ICT infusion, either in the form of e-health, telemedicine or m-health programmes, follows a steady upward trend both in developed and developing member countries. In particular, 58% of WHO member states already run their own e-health strategies, while almost 80% reported that their national healthcare organizations employ social media applications for distributing messages and promoting health campaigns. According to the same study, 87% of the responding countries already have an m-health programme, while almost 50% have a tele-pathology, remote patient monitoring and tele-dermatology programme. It should be noted that the results of the WHO (2016) survey indicate significant growth in most areas since the 2010 global survey. Consequently, it has become apparent that the infusion of ICT in the healthcare sector is no longer a vision for the future, but a part of everyday life.

However, research has identified a group of factors associated with financial, legal, and trust issues that decelerate the development of e-health, telemedicine and m-health strategies and programmes both in developed and developing countries (Lee and Zuercher, 2017; WHO, 2016; OECD, 2013). Indeed, high costs associated with the implementation of any kind of

telemedicine programme is the most frequent obstacle cited (WHO, 2016:7). According to the WHO (2016), the implementation of e-health programmes demands significant, upfront investment for setting up IT infrastructure, as well as costs associated with evaluation and operations. Legal issues are often reported as the second most dominant barrier. In particular, according to a study conducted by the OECD (2013), privacy issues were found to be among the most significant obstacles in relation to the implementation of an e-health programme. Finally, it is stressed that concerns associated with trust issues have been identified as one of the barriers that prevents the widespread use of remote communication between patient and physician (Lee and Zuercher, 2017). However, not enough is known about the role of *trust* and the way it works within the health sector in this new digital context.

At this point it would be of critical importance to explicitly define two key- terms that dominate my thesis, namely, *computer-mediated communication* (CMC) and *information and communication technologies* (ICT). Within the framework of the current thesis, the term *computer-mediated communication* (CMC) encompasses all human communication conducted via *information and communication technologies* (ICT), such as mobile phones, computers, tablets, digital platforms of communication (chat rooms, etc.), applications (apps) for asynchronous or synchronous communication via smartphones and tablets, video-conference platforms and software, as well as e-mail services and social media platforms. It's worth underlining that ICT as a term (especially in the ICT4D¹ literature), often encompasses long-established technologies and devices, such as landlines, fixed telephone devices, fax devices and radios. It is highlighted that in my thesis the term *remote communication* is used interchangeably with CMC. To be more precise, I have chosen to use CMC in addition to *remote communication* because I draw on a body of literature that uses this term. However, both terms imply all human communication via ICT.

ICT could be classified in terms of *interactivity*, *asynchronous* and *synchronous*. *Synchronous* ICT refers to media which offer the potential of bidirectional communication on a real-time basis, such as fixed phone devices, mobile phones, video-conference devices and computer applications, chat rooms, etc. *Asynchronous* refers to ICT which do not offer bidirectional communication on a real-time basis, such as e-mail services, voice-mail services, FAX devices,

¹ Information and Communication Technologies for Development

video messaging applications or SMSs. However, ICT could also be classified in terms of *modality*, i.e. *linguistic* and *visual* modes. For instance, e-mail, phone devices, voice-mail services and FAX do not provide visual access, whereas video-conference applications provide channels for transmitting both linguistic and visual information (facial expressions, nods, gaze, gesture, etc.).

1.2 Trust: the under-explored item in the digital health research agenda

On the one hand, policy makers and academics seem to be well informed about global trends of ICT infusion and to be able to talk about them in quantitative terms in detail. The same is true concerning legal and financial barriers that prevent the widespread use of remote communication between patients and physicians. On the other hand, such practitioners and scholars seem to have marginal knowledge not only about the patient-healthcare expert remote communication itself (Lee and Zuercher, 2017) but also about key-aspects of a qualitative nature, such as the role of *trust* in the light of remote communication (Andreassen *et al.* 2006; Santana *et al.*, 2010). Although a small number of scholars from the field of e-health have supported that remote communication between healthcare professionals and patients could improve patient care leading to greater levels of *trust* (Andreassen *et al.*, 2006; Nilsson *et al.*, 2010; Shea and Effken, 2008; Simpson, 2009) the role of *trust* remains largely unexplored.

It was Andreassen *et al.* (2006) from the field of e-health who stressed that “[c]onstructing e-mediated communication practices that promote trust and patient involvement will need careful consideration” (p. 246). Similarly, Santana *et al.* (2010) indicated that trust, *inter alia*, in the light of electronic communication between healthcare providers and patients, remains unclear and needs to be addressed. Furthermore, acclaimed sociologists have expressed concerns with regard to the controversial effect of ICT on the element of trust as a primal matter of our societies, in general (Giddens, 1990; Beck, 1992; Riegelsberger, 2003), and the health sector in particular (Nettleton and Burrows’, 2003). However, there is no relevant research work regarding the role of trust in the field of the patient-healthcare expert remote communication, since the latest call for research by Santana *et al.* (2010).

It is of critical importance both for scholars and policy makers to be aware of the role of trust in the light of remote communication for two key-reasons. The first one regards trust as the

core element of the patient-healthcare expert relationship. The patient-physician relationship literature has, so far, clearly demonstrated that the patient-to-physician relationship is one grounded on trust (Hillen *et al.*, 2011; Thom and Campbell, 1997; Hall *et al.*, 2002; Toafa *et al.*, 1999; Shea and Effken, 2008; Dinç and Gastmans, 2012), since the trustor called patient, finds him/herself in a vulnerable position in the light of a severe, or possibly severe, health issue, that they cannot treat or manage on their own. In other words, the patient places the fate of their health, not to mention their life, in a trustee called physician, who claims to have expertise, something that is not in the patient's control. In brief, patients grant physicians "discretionary powers, which include the power to help or harm" (Rogers, 2002:77) them. In the light of a serious health issue, that asymmetry in terms of expertise is transformed to a power asymmetry. Given the key-role of trust in the patient-healthcare expert relationship, there is an imperative need to respond to scholars' call for studying trust in the light of the patient-physician remote communication (Lee and Zuercher, 2017; Andreassen *et al.* 2008; Santana *et al.*, 2010; Nettleton and Burrows', 2003). A research based on first-hand data collected by healthcare experts themselves making use of ICT in their communication with their patients for strictly medical purposes is expected to shed light onto the role of trust in that under-researched mode of communication.

There are also financial and policy issues that make the need for research in the remote patient-healthcare expert communication imperative. Public deficit issues in the EU demand immediate cost-curtailing actions across the entire range of public investments and activities. The health sector, i.e. the cornerstone of the EU social market economy, could not be left out. According to EU health policies and strategies, reforms and innovative initiatives (*see* digital transformation policies) are expected to make the EU health system more solid in terms of efficiency and productivity. In my view, investing in e-health, m-health or telemedicine strategies without having assessed or even estimated their effect in terms of trust in professionals or systems, would put their returns at risk in terms of sustainability and money. It should not be forgotten that the expectations held by the European Commission for dramatic cost reductions through the implementation of ICT in the health sector takes place in an era where *trust in professionals* and *expert systems* should not be taken for granted (Popper, 1962; Giddens, 1990).

1.3 Research questions, aims and objectives

The research question addressed in the current thesis is this:

How do self-employed healthcare experts experience remote communication with both their patients and their patients' carers -in the light of trust- via ICT designed for commercial purposes?

In other words, the research aim of the current PhD thesis is:

To provide advance understanding of how healthcare professionals experience remote communication with their patients -or with their patients' carers- in cases when it is impossible for the patient to communicate effectively, placing special emphasis on the element of trust.

In particular, my research objectives are to:

- use original qualitative evidence to explore how trust is implicated in the adoption of remote communication from the perspective of independent healthcare professionals;
- contribute to the theory about the intersection of trust and digital technology in contemporary medical practice, and finally,
- assess implications of independent healthcare professionals' responses to remote communications for the wider uptake of ICT in the health sector.

The exploratory nature of my research question imposed a qualitative research path using an inductive approach. I would consider it of crucial importance to highlight that the current study *draws upon* GT techniques, as described by Charmaz (2014), rather than being a pure GT study *per se*. Data were collected from sixteen healthcare private practitioners who claimed that remote communication with their patients is part of their daily, professional routine. Specifically, the group of private practitioners comprises eight physicians (three paediatricians, one obstetrician/gynaecologist, one dentist, one ophthalmologist, one physician, one diabetes expert) and eight mental-health experts (two psychiatrists oriented in talk-therapy and six psychotherapists of various schools of thought).

1.4 A different perspective on the patient-healthcare expert remote communication

The current PhD thesis differs from most research within the genre in the makeup of the sample of interviewees and the concept under study. In sharp contrast to existing literature, the current thesis draws on the experience of private practitioners' remote communication with their patients, while making use of ICT devices and applications designed for private rather than medical use. Such ICT encompass a wide range of devices from old-school landline telephones to the more modern desktop computers, laptops, tablets and smart phones, which are capable of supporting both audio and video communication, as well as data-sharing, such as photos, videos and voice mail. All relevant research work in this genre has so far drawn on the experiences of healthcare staff, such as physicians, mental-health experts and nurses, who used to communicate with their patients remotely through a text-based platform hosted by a public hospital as part of a structured telemedicine programme (Andreassen *et al.*, 2006; Nilsson *et al.*, 2010; Shea and Effken, 2008).

In contrast to previous research work, I draw on experiences from the unexplored field that I define as *over-the-counter telemedicine*. That is, the implementation of any medical act that can be implemented in remote via ICT, which is designed for personal rather than medical communication. In other words, *over-the-counter telemedicine* encompasses any remote communication between the patient and the healthcare expert concerning a medical issue or request on behalf of the patient, which leaves no trace in any national health records system. A common example of *over-the-counter telemedicine* is the parent-to-private practice paediatrician communication by phone regarding a child's medical issue, such as a cold or fever. I consider that once the paediatrician actively responds to a parent's request to provide a treatment plan or guidance, he/she implements medicine in remote, i.e. telemedicine. Nevertheless, that kind of remote interaction is not subjected to any hospital code of conduct or hospital protocol about handling the patient's request for remote communication via phone calls. In other words, the use of ICT is subject to the discretion of the healthcare expert. Meanwhile, that medical interaction leaves no footprint in any hospital or national health records system, especially when communication is verbal. To the best of my knowledge, this sort of interaction between private practitioners and their patients remains unexplored by the research community and policy makers.

1.5 The structure of my PhD thesis

The current thesis is comprised of eight individual chapters including the introduction (Chapter 1) and conclusions (Chapter 8).

Chapters 2 and 3 encompass relevant literature on research already conducted and draws knowledge and experience from three individual research areas: (a) trust literature, (b) CMC theories and (c) the patient-healthcare expert relationship. Chart 1.5 graphically represents the interdisciplinary nature of the literature review and the thesis, as well. In more detail, Chapter 2 offers a wide spectrum of definitions, synonyms and misconceptions of trust across different disciplines. The emphasis is on trust in the patient-healthcare expert relationship and its components. Finally, it identifies unexplored and “grey” areas of the patient-healthcare expert relationship, suggesting areas for further research, such as the aspect of *mutuality* in the patient-healthcare expert relationship, the concept of the *trustworthy patient* and the carer-physician relationship.

Chapter 3 attempts to place the current thesis within the broader sociological discussion regarding the digital transformation taking place in the health sector from a power, risk, skills and, finally, trust perspective. In particular, it provides a historical background regarding the evolution of the patient-physician relationship from a power balance perspective, and the major transformations taking place in recent years due to the ICT invasion into the health sector. This chapter also includes a critical approach of the new patient-physician relationship in terms of power balance through the lens of trust and skills. Additionally, special reference is made to human senses as an epistemological tool for healthcare experts. Chapter 3 ends with an attempt to place the current PhD thesis within the contemporary sociological landscape of Beck’s *risk society*.

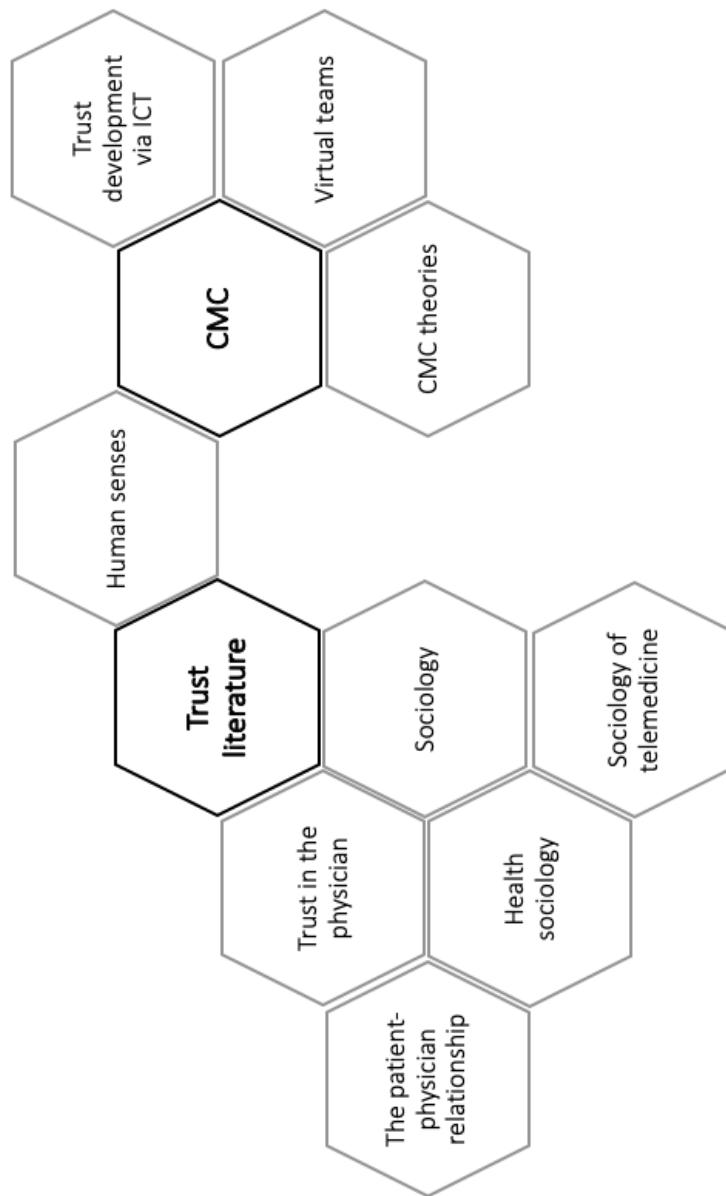


Chart 1.5
The interdisciplinary synthesis of the literature review

Chapter 4 begins with a brief review of old, yet influential, theories about the effect of computer-mediated communication (CMC) on social as well as personal interactions. It also provides a review of the literature which studies trust formation and development via CMC in

various contexts. Emphasis is given to interpretivists' voices challenging well-established ideas on the perception of risk and affordances in the light of CMC. Chapter 4 ends with a review of the very limited literature studying the role of trust in CMC between patients and healthcare experts.

Chapter 5 provides a detailed account with regard to my methodological choices. It begins with an insight into my ontological and epistemological conceptions underpinning the rationale behind my methodological choices and how these affected my decision to *draw upon* the constructivists' grounded theory approach and techniques. It also demonstrates the criteria used for sampling, as well as the coding techniques employed for data-analysis. Actions taken in order to generate a valid and credible research output are demonstrated. Additionally, the chapter provides personal reflections and accounts about challenges that arose during the stages of research design, data-collection and data. Finally, ethical issues are addressed in as much detail as possible.

Chapter 6 introduces, explores and unravels, for the first time, the under-researched aspect of mutuality in the patient-healthcare expert relationship and, hence, the theme of the *trustworthy patient (carer)*. Moreover, Chapter 6 links *the trustworthy patient's/ carer's* (TP/C) web of skills with the healthcare experts' *risk perceptions*. Additionally, the chapter provides a detailed taxonomy of the medical data theme and how this theme is linked with the TP/C's *communicational skills*. Chapter 6 ends with an integrated diagram that attempts to relate the TP/C's *communicational skills*, the theme of *medical data* and the healthcare experts' *risk perceptions*.

Chapter 7 demonstrates that it is important for physicians and MHEs to *know their patients* before they decide to provide any medical guidance remotely, making use of ICT, yet not to the same extent for each group. There are a number of factors that healthcare experts consider before they provide any remote guidance for medical purposes. However, this set of factors was not identical for all healthcare experts. In fact, MHEs and physicians do not focus on the same factors. Physicians focus on (a) *patient's trustworthiness* in terms of *communicational* and *aptitudinal skills*, (b) *patient's regularity* in terms of visits, and (c) patient's attitude towards ICT (*overuser*). MHEs focus on (a) *a patient's psychopathology* in terms of *risk*, (b) *feasibility of*

face-to-face sessions and, finally, (c) *contribution of remote sessions to therapy*. Finally, great emphasis has been placed on the role of the medium's *perceived affordances*.

Finally, Chapter 8 presents an extensive discussion of the emerging theory and the secondary findings that arose during the current research project. In particular, Chapter 8 begins with an integrated model of the themes thoroughly described in Chapters 6 and 7. Then follows a discussion of the emerging theory in the light of power and trust, as well as an extensive discussion of the value of the *know-my-patient* principle when distance makes CMC the only possible way of communication. Moreover, Chapter 8 provides a discussion regarding the value of healthcare experts' accessibility via ICT and physicians' trust in the patient through from the perspective of trust literature. Additionally, a note concerning the *patient's work* and *skills* in the digital-health landscape is provided, along with a discussion regarding the healthcare experts' medium selection decision. Finally, an extensive report is presented regarding implications for policy and practice. Chapter 8 ends with an account of the contribution of the current doctoral thesis to knowledge, the limitations recognised and a number of suggestions for future research.

Chapter 2

Trust: definitions, subcategories, misconceptions & synonyms

Chapter 2 begins with a variety of trust definitions drawn from the field of social psychology, computer-mediated communications (CMC), philosophy, sociology and, finally, from the field of economics and business management. Following on, after the definitions, there are a number of subcategories, synonyms and misconceptions about trust. Great emphasis is placed on trust definitions coming both from the patient-doctor and patient-nurse relationship literature. There then follows a special note with regard to the value of trust in the carer-healthcare expert relationship. Chapter 2 ends with thorough reference to under-researched aspect of mutual trust in the patient-doctor trust-relationship.

2.1 Defining trust

Goudge and Gilson (2005), advising researchers studying trust, stressed the importance of working to establish a well-grounded definition to “ensure that respondents’ answers refer to the form of trust under investigation” (p. 1439). Similarly, Mayer *et al.* (1995) recognized the lack of a universal definition as a limitation in organisational and management studies that focus on trust. Though trust has been a popular research subject in a variety of scientific realms, it is still considered by many scholars as difficult to define and, therefore, to investigate (Blomqvist, 1997; Giddens, 1990).

The field of *social psychology* offers plenty of trust definitions formulated by prestigious scholars. According to Deutsch (1958), from the field of *social psychology*, trust is composed of two critical elements: *confidence in ability* and *intention*.

“An individual may be said to have trust in the occurrence of an event if he expects its occurrence and his expectation leads to behaviour which he perceives to have greater negative motivational consequences if the expectation is not confirmed, than positive motivational consequences if it is confirmed” (p.266)

Similar to Deutch's (1958) definition, Scanzoni (1979) described trust as

"...actor's willingness to arrange and repose his or her activities on other because of confidence that other will provide expected gratifications." (Scanzoni, 1979, cited in Rempel *et al.* 1985:95)

According to Rotter (1967), trust is defined as

"an expectancy held by an individual or a group that the word, promise, verbal, or written statement of another individual or group can be relied on [...] a generalized expectancy held by an individual that the word, promise, or statement of another individual can be relied on" (p.651)

emphasising *reliance* as an integrated part of trust, similar to Deutch's (1958) definition.

Rousseau *et al.* (1998) defined trust as

"...the intention to accept vulnerability based upon positive expectations of the intentions or behavior of another" (Rousseau *et al.*, 1998, cited in Collquit *et al.*, 2007)

The golden thread that connects trust definitions mentioned above is the one of *expectations*.

Similar to Rotter (1967), Blau (1964) supported that

"Parties can gradually build trust in each other through social exchange demonstrating a capacity to keep promises and showing commitment to the relationship." (Blau, 1964, cited in Blomqvist, 1997:273)

According to my interpretation, there is no major divergence in the views by the scholars mentioned above with regard to the way they perceive the concept of trust. Trustors find themselves in a vulnerable position, since they rely on the trustees' skills and good intentions for the fulfilment of such expectations. In my context, i.e. patient-doctor relationship, it is the patients who find themselves in a vulnerable position, since they lack the expertise required for identifying, managing and, finally, eliminating risks stemming from a physical or mental illness. For example, lack of a physician's good intention may lead patients to a number of unnecessary medical tests and exams, even if these might not necessarily be harmful for the patients' health.

Scholars who study trust development between work teams sharing the same task via *computer-mediated communication* also provide plenty of definitions. Wilson *et al.* (2006) define trust as “positive expectations about the conduct of another” (p. 18), breaking it down into two elements: *risk* and *reliance* (Gambetta, 1988; Rousseau, Sitkin, Burt and Camerer, 1998). For instance, team members could be exposed to a status of risk if other group members do not make the same effort in terms of commitment to targets or working hours towards the achievement of their common goal. Reliance is defined as bearing the risk to depend on others’ commitment. In brief, they would expect that

“...trust gives group members the confidence to take risks and act without concern that other group members will take advantage of them (McAllister, 1995)” (Wilson *et al.*, 2006:18)

Riegelsberger *et al.* (2003) accept what Corritore *et al.* (2001) define as ‘abstract definition’, where

“...trust is the willingness to be vulnerable based on positive expectations about the actions of others” (Riegelsberger, 2003:761)

To sum up, scholars from the field of CMC place the elements of risk and expectations at the core of trust, just as social psychologists have done. However, it is worth noting that definitions coming from CMC and ICT4D do not make any direct reference to skills, competence or abilities. Instead, they place more emphasis on risk exposure, which is found to be at the core of trust.

The study and definition of trust has always been a major issue in *philosophy*. Blomqvist (1997) reports four different definitions of trust from the realm of philosophy, emphasising that philosophers often perceive trust ‘as an unconscious basic conduct of life’ (p. 274). According to Baier (1986), trust is an

“...accepted vulnerability to another's possible but not expected ill will (or lack of good will) towards one. It is reliance on the other's competence, and willingness to look after, rather than harm, things one cares about which are entrusted to the other's care” (cited in Blomqvist, 1997:274).

Trust has been also perceived as

“a Passion proceeding from the Belief of him from whom we expect or hope for Good, so free from Doubt that upon the same we pursue no other Way to attain the same Good” (Hobbes, 1750, cited in Blomqvist, 1997:274)

I hold the view that Hobbes (1750) approaches the element of *faith* rather than the one of *trust*, given that trust encompasses calculation or estimations and, finally, low or high expectations. I would consider that the phrase “*so free from Doubt*” cancels the aspect of calculations based on rational expectations offering an almost theological perspective of trust. Similar to Hobbes (1750), Lagerspetz (1992) approaches trust emphasising that no evidence is provided to support a trustor's beliefs.

According to Lagerspetz (1992),

“...trust seems to involve beliefs which are not accepted on the basis of evidence and beliefs which in some case might be highly resistant to evidence that runs counter to them” (cited in Blomqvist, 1997:274)

Trust has also been perceived as ‘(Beliefs that) are tolerated and indeed, valued’ (Baker, 1987, cited in Blomqvist, 1997:274). It is worth highlighting that similar to both Lagerspetz and Hobbes, Baker (1987) made use of the term *belief*, which, according to my interpretation, is far from any calculation. To my understanding, belief in [a] God is not based on calculations, as Gambetta (1988) supports:

“the probability that he will perform an action that is beneficial or at least not detrimental to us is high enough for us to consider engaging in some form of cooperation with him” (p. 217)

Baier (1986) observed that major *moral philosophers*, such as Plato or Aristotle, have never made direct reference to the concept of trust. Instead, they imply trust when they deal with aspects of social life, such as friendship, cooperation, etc.

Anthony Giddens and Niklas Luhmann are considered pioneer scholars in the study of trust in *sociology*. According to Giddens (1990),

“trust may be defined as confidence in the reliability of a person or system, regarding a given set of outcomes or events, where that confidence expresses a faith in the probity or love of another, or in the correctness of abstract principles (technical knowledge),” (p. 34)

while Luhmann (2000) accepts that trust is the ‘glue’ that brings cohesion in social life while reducing complexity in the postmodern environment of chance and risk (see Beck’s *risk society*). As Luhmann (2000) underlines,

“if this is true [...] we are likely to enter sooner or later into the vicious circle of not risking trust, losing possibilities of rational action, losing confidence in the system, and so on being that much less prepared to risk trust at all. We may then continue to live with a new type of anxiety about the future outcome of present decisions, and with a general suspicion of dishonest dealings.” (p. 105)

Gambetta (2000), from the realm of sociology, offers a definition which denotes key aspects of Dasgupta’s (2000) definition, such as that of *monitoring*.

“trust (or, symmetrically, distrust) is a particular level of the subjective probability with which an agent assesses that another agent or group of agents will perform a particular action, both before he can monitor such action (or independently of his capacity ever to be able to monitor it) and in a context in which it affects his own action” (page number not available)

However, it is worth highlighting that both Luhmann (2000) and Gambetta (2000) emphasise the aspect of *subjectivity*. In other words, they support that both risk perception and risk assessment are subject to personal interpretation. Lewis and Weigert (1985) approached trust from a sociological rather than psychological perspective, in a way verifying, Luhmann’s perception about trust as a necessary factor for reducing complexities. According to Lewis and Weigert (1985),

“...trust reduces complexity far more quickly, economically, and thoroughly than does prediction. Trust allows social interactions to proceed on a simple and confident basis, where, in the absence of trust, the monstrous complexity posed by contingent futures would again return to paralyze action” (p. 969)

In sharp contrast to the definitions provided by the scholars of philosophy, in sociology it is the aspect of calculation that is present instead of 'hopes for Good' (Hobbes, 1750). For example, Gambetta (2000), as well as Lewis and Weigert (1985) in their attempt to map trust, make use of terms such as *prediction*, *rational prediction*, *probability*, or *assessment* unravelling the calculus dimension of trust.

The element of trust has also drawn the attention of *economists* and *business management* scholars, since it is considered by many a significant lubricant of economic life due to its ability to reduce transaction costs. According to Dasgupta (2000), from the field of *economics*, *trust* is defined as

“...expectations about the actions of other people that have a bearing on one’s own choice of action when that action must be chosen before one can monitor the actions of those others,” (Dasgupta, 2000, cited in Molony, 2007:69)

which bears close resemblance to McAllister’s (1995) definition. Sako (1998), from the field of business management, defined trust as

“...an expectation held by an agent that its trading partner will behave in a mutually acceptable manner (including an expectation that neither party will exploit the other’s vulnerabilities).” (Sako, 1998:3)

emphasising, as Dasgupta did, the aspect of *expectations*. Similar to Luhmann (1988), who believes that trust is a factor which leads to the establishment of higher social cohesion levels, Sako (1998) supports that trust empowers business performance, highlighting the role of trust as a contributing factor of success in terms of partnerships, strategic alliances and networks, particularly for small firms.

Finally, Sabel (1993) defined trust as “...the mutual confidence that no party to an exchange will exploit the other's vulnerability” (Sabel, 1993:1133), while Noorderhaven (1992) underlined that “trust denotes the willingness to engage in a transaction in the absence of adequate safeguards.” (Noorderhaven, 1992, cited in Blomqvist, 1997:275)

According to Lorenz (1988),

“trusting behavior consists in action that 1) increases one's vulnerability to another whose behavior is not under one's control, and 2) takes place in a situation where the penalty suffered if the trust is abused would lead one to regret the action.” (Lorenz, 1988, cited in Blomqvist, 1997:275)

Mayer *et al.* (1995) offered a definition which is adopted as a working hypothesis in numerous papers. According to Mayer *et al.* (1995),

“trust is the willingness of a party to be vulnerable to the actions of another party based on the expectation that the other will perform a particular action important to the trustor, irrespective of the ability to monitor or control that other party.” (p. 712)

At this point it should be highlighted that Mayer *et al.* (1995) recognised that trust encompasses more than one component. In particular, they found that *ability*, *benevolence* and *integrity* are included in various efforts to deconstruct trust into more than one component. *Ability* refers to the group of skills and competencies that define one as an expert. As explicitly shown in the following section, a review of the patient-doctor literature reveals that a physician's expertise is one factor, among others, that makes him/her trustworthy (Thom and Campbell, 1997; Hall *et al.*, 2002; Hillen *et al.*, 2011). *Benevolence* refers to the intention of a party to do the best for the interests of the other party, far from any 'egocentric profit motive' (Mayer *et al.*, 1995:718). Finally, *integrity* exists when the trustor believes that the trustee is adherent to a group of principles and beliefs which are espoused by the trustor (Mayer *et al.*, 1995).

To sum up, it is clear that *risk* is the common ground among definitions provided in this section, regardless of the discipline they come from. If we exclude definitions coming from the field of *philosophy*, scholars from various fields highlight that, in the absence of risk, there is no trust issue. It is noted that a number of definitions were left out of my literature review because I considered they would not offer a different perspective compared to the ones presented. However, there are plenty of definitions in trust literature with regard to subcategories of trust.

2.2 Subcategories of trust

Gulati and Sytch (2008) separated trust into *dispositional* and *relational* trust, where dispositional trust refers to our expectations from others in terms of trustworthiness, while

relational trust refers to a '*specific dyadic partner*' (Gulati and Sytch, 2008:167). Pearson *et al.* (2000) also made a distinction between *social* and *interpersonal* trust.

"Interpersonal trust refers to the trust built through repeated interactions through which expectations about a person's trustworthy behavior can be tested over time. Social trust however, is trust in collective institutions, influenced broadly by the media and by general social confidence in particular institutions" (p. 510)

Molony (2007) distinguished trust as *minimal* and *extended*;

"Minimal trust is concerned with the fulfilment of explicit promises required for basic market transactions and must be in place for extended trust to develop. Extended trust is created when relationships require more complex interactions and interdependencies such as those found in supply chains and clusters." (p. 69)

Giddens (1990) separated *personal* from *impersonal trust*, in that the personality of the participants is irrelevant for the development of impersonal trust. Giddens' (1990) had explicitly bridged *impersonal trust* (trust in experts and *abstract systems*) with *personal trust* (personal trust), arguing that impersonal trust presupposes and is determined by *personal trust*. In other words, trust in the healthcare provider is a prerequisite for trust in the health system.

Furthermore, Blomqvist (1997) noted that Luhmann (1989) separates *universalistic* trust from *particularistic* trust. Particularistic trust is the form of trust which results from the social characteristics of the other instead of individual ones, while universalistic trust is interpreted by Blomqvist (1997) as synonymous to what Noorderhaven calls *personal trust* (trust based on personal knowledge of the other). However, as I mentioned before, it was Lewicki and Bunker (1995) who also mentioned this specific kind of trust i.e. 'knowledge-based trust' (p. 149).

Sako (1998) recognises three types of trust: *contractual* trust, *competence* trust and *goodwill* trust. *Contractual* trust assumes both parties' agreement on a code of ethics which are expected to be honoured, while *competence* trust rests on the trustees' skills and abilities to do what they promised. *Goodwill* trust encompasses the absence of opportunistic behaviour

as well as the will to over perform.

Lewicki and Bunker (1995) suggested that there are three types of trust: *calculus*, *identification-based* and *knowledge* trust. *Calculus* trust is related to the consequences of the violation of trust and/or the rewards associated with preserving trust. In brief, it is based on the assessment of costs and benefits in the light of a positive or negative scenario. *Identification-based* trust lies on mutual trust and is built when the two parties aim at the same goals while being fully aware of each other's wishes. *Knowledge-based* trust was found to play a critical role in the patient-doctor remote communication –i.e., the core of my study- and, thus, I would consider it important to provide a more detailed description of the importance of knowing the other when building trust.

“The better I know the other, the better I can trust what the other will do because I can accurately predict how they will respond in most situations” (Lewicki and Bunker, 1995: 149)

Knowledge-based trust is built on our knowledge about the other party. According to Lewicki and Bunker (1995), being aware of the other contributes to predicting his/her behaviour or actions. Being aware of «who is who» in a relationship that relies on trust (i.e., marriage, expert-to-non-expert) also helps assess whether the other party deserves our trust or not (untrustworthy). The aspect of regularity in communication seems to play a vital role in knowledge-based trust, since continuous interaction offers an increasing volume of data about the other party. Regular communication enhances our ability to learn about the other party's values, desires and preferences. The more we know about the other, the better we know him/her.

Similar knowledge about the value of *knowledge-based* trust can be drawn from the field of patient-nurse relationship. *Knowing the patient* is defined in the nursing literature as the ‘in-depth knowledge of the patient's patterns of responses and knowing the patient as a person’ (Tanner *et al.*, 1993:275). Similarly, Radwin (1996) conducted a literature review and found that *knowing the patient* was a recurring theme grounded in two components: “the nurses’ understanding of the patient and the selection of individualized interventions” (p.1142). Nilson *et al.* (2008) from the field of tele-nursing, reported that district nurses “emphasized that knowing the ill person engendered feelings of security and made it easier to predict what

would happen” (p. 262). Moreover, a more recent literature review by Zolnierrek (2014) identified that *knowing the patient* was associated with (a) the assessment, planning and implementation of nursing care, (b) building positive relationships with patients, and (c) deliverance of expert practice.

The value of *knowledge-based-trust* has also been stressed in virtual organisation literature. As Handy (1995) underlined “[p]aradoxically, the more virtual an organization becomes, the more its people need to meet in person” and meetings in virtual organisations should ensure that “people get to know each other [...] as people, not just as images on the screen” (p._). In other words, Handy (1995) stresses that face-to-face interactions between the team-members of virtual organisations (i.e., *touch*) contributes to getting to know each other. Face-to-face interaction, such as work and play, promotes trust development between virtual-team-members that is expected to reinforce “corporate goals and rethinking corporate strategies” (p._). In brief, Handy (1995) supports that “the more virtual an organisation becomes, the more its people need to meet in person.” (p._).

Finally, according to my research, too little is known about the aspect of knowledge-based trust and the theme of *knowing my patient*; this is particularly so within the field of patient-doctor communication, whether face-to-face or remotely. Langley and Klopper (2005) mentioned that knowing the patient is perceived by mental-health practitioners as a necessary component of their trust-based relationship with patients suffering from borderline personality disorders. To *know the patient* is to be aware of their full history, strengths and behavioural patterns among other things (Langley and Klopper, 2005). It should not be considered as a coincidence that Gibson et al. (2015) emphatically mentioned that “[t]he ‘remote’ nature of the consultation posed challenges for some patients” (Ginson et al., 2015:98-99) which could be further eased by clear information about clear information with regard to who is the patient or carer in charge. Finally, Andreassen *et al.* (2006) from the field of patient-doctor remote communication found that it was important for patients to *know the doctor* before instigating computer-mediated communication.

At this point it is worth noticing that there are subtle indications that *knowing the patient* as a *whole person* (Finch *et al.*, 2008) is of critical importance for designing an effective

telemedicine platform. *Knowing the patient as a whole person* means approaching the patient holistically instead of dealing with a cluster of medical data, as is the case in telemedicine and tele-dermatology, in particular. *Fragmenting the patient* (Finch *et al.*, 2008) into bits of medical information deprives healthcare experts from knowledge that is not strictly medical, yet often critical for achieving a valid diagnosis.

“A lot of the information which you get from a patient relates to issues other than the actual clinical diagnosis. In other words, the impact that a skin problem might be having on them, for example. So, we might have two people who've got what is, visually, an identical looking rash. One of them might be completely not bothered but the other person might be devastated. And those sorts of more subtle clues about patient's anxiety and the impact the problem is having on them, I suspect will be a lot more difficult to get with teledermatology.” (Mort *et al.*, 2003:284)

Finch *et al.* (2008), from the field of sociology of medicine, have stressed that there are studies indicating the problematic nature of telemedicine in that it often deprives healthcare experts from knowing their patients' psychosocial state, levels of anxiety, fears and concerns, their family status or family life, etc.

On the hand, there is a number of papers that demonstrate the power and value of *prior knowledge* between the patient and the healthcare expert, both in the traditional face-to-face and in remote communication settings (Tanner *et al.*, 1993; Radwin, 1996; Langley and Klopper, 2005; Andreassen *et al.*, 2006). On the other hand, limited findings from the field of patient-healthcare expert e-mail communication challenged the effect of *prior knowledge*. In particular, Tate *et al.* (2001) found that adding e-mail counselling to a structured internet behavioural weight loss programme could improve patients' levels of effectiveness, although neither the healthcare expert nor the patient had had any face-to-face or previous acquaintance before exchanging e-mail messages. Similar results were reported by Dunbar *et al.* (2003) who found that a two-way messaging system for establishing remote communication with HIV-positive patients empowered adherence to the treatment regime. It is highlighted that no previous knowledge between the healthcare expert and the patient existed prior to their remote communication.

Trust definitions and subcategories are inexhaustible and quite context-dependent. Although a number of subcategories and kinds of trust have been mentioned by various scholars in their attempts to understand trust in very specific contexts, a number of relevant terms have also appeared as misconceptions or synonyms of trust.

2.3 Synonyms and misconceptions of trust

Mayer *et al* (1995) made extensive reference to *cooperation*, *confidence* and *predictability* as terms that are often used interchangeably with trust, without being synonymous. Their argument is that though trust may lead to cooperation between two parties, trust is not a prerequisite for building a cooperative relationship, because cooperation does not necessarily place a party in a risky position. Consequently, Gambetta's opinion that trusting someone means

“the probability that he will perform an action that is beneficial or at least not detrimental to us is high enough for us to consider engaging in some form of cooperation with him” (Mayer *et al.*, 1995:712)

could be characterised as unfounded, since cooperation is possible for two parties even in the absence of trust. *Confidence* is also considered as a concept closely related to trust. It is underlined that Deutsch makes use of the term confidence to define trust

“...the extent to which one is willing to ascribe good intentions to and have confidence in the words and actions of other people” (Deutsch, 1960, cited in Mayer *et al.*, 1995:713)

According to Luhmann (2000), the individual who does not need to choose between two or more options is in a state of confidence. This is in sharp contrast to one who considers alternatives and, thus, is found to be in a state of trust. I share Giddens' (1990) interpretation in that a person whose expectations are not fulfilled while being in a state of confidence will immediately attempt to shift the burden of responsibility onto others. On the contrary, a person whose expectations were not fulfilled while being in a state of trust will possibly share the responsibility.

Blomqvist (1997) detected a group of terms, such as *credibility*, *sincerity*, *competence*, *hope*, *loyalty* and *reliance*, which are often used interchangeably with that of trust, or as a substitution of the term 'trust'. Within the framework of the following paragraph, I offer a personal account of trust synonyms, rather than other scholars' accounts.

2.4 A personal account on misconceptions and synonyms

A thorough study of trust definitions provided in the previous section served as a toolkit, which enabled me to make the distinction between trust synonyms less complex. According to my interpretation, a *credible* person is one who fulfils his/her trustee's expectations. Thus, a *credible* person is often found to possess both moral values (i.e., good will) and skills. The individual lacking a commonly acceptable set of ethical values or a set of skills could hardly be considered as *credible*. In that sense, it seems that the term *credible* could be considered as an actual synonym of *trustworthy*. In that sense, a person who has good intentions is a person who has nothing to mask/hide and, thus, he/she is one who demonstrates *sincerity*. However, the quality of *sincerity* is not related to skills. I would consider *sincerity* as a quality of a credible person. It is the quality of *competence* directly linked to the set of skills that a credible (trustworthy) person possesses.

Hope is considered another closely associated concept to that of trust (Blomqvist, 1997). However, *hope*, as a social construction, is subject to various interpretations. For example, a person who hopes could possibly be a person who does not possess the set of skills demanded to deal with a risky situation. It should not be forgotten that, in the absence of risk, there is no trust issue. However, a person who hopes could possibly be a person who has done the best they could, waiting for the *Deus ex machina* to contribute to the achievement of the positive scenario. So, I would not consider *hope* as a synonym for *trust*.

Blomqvist (1997) defines as *loyal* "the actor [who] has taken a faithful stand relative to another actor, behaving totally positively towards that actor's need" (p.279). Blomqvist (1997) qualifies *loyalty* with the temporal attribute of long-lasting. According to my understanding, *loyalty* is interwoven with the moral aspect of trust rather than with that of abilities. I would agree with Blomqvist on the temporal aspect of *loyalty*. 'Loyal' is used to describe someone who shows long term commitment (i.e., a loyal friend, a faithful husband, etc.).

Finally, a company that fulfils its shareholders' expectations concerning profitability, in terms of dividends distributed, is a *reliable* one. Consequently, it could be supported that *reliance* implies abilities and effectiveness. However, Blomqvist (1997) perceives reliance as a much narrower term than trust, as only certain aspects are relied upon. However, it should be noted that the way the above-mentioned terms are interpreted and used in Greek, could possibly influence the way I perceive and, ultimately, define them.

2.5 Defining trust in the medical setting

Beck *et al.* (2002) underlined that when the patient-doctor relationship is studied under the research scope of social sciences, scholars are often faced with a lack of consensus as to what to measure. Hillen *et al* (2011) undertook a review of the literature on cancer patients' trust in their physician and found that in 34 studies out of 45, the term 'trust' lacked clarification, while in the rest of the papers, trust was defined in various ways. The following paragraphs aim at providing an overview of the components of a patient's trust in doctors and nurses. The under-researched *carer-doctor relationship* and the aspect of *mutuality* in the patient-healthcare expert relationship are also unravelled.

2.5.1 Defining *trust* in the patient-physician relationship

Thom and Campbell (1997) made one of the very first efforts to conceptualise the patient-physician trust from an exploratory perspective. They segmented trust into the following nine elements:

1	Thoroughly evaluating problems
2	Understanding patient's individual experience
3	Expressing care
4	Providing appropriate and effective treatment
5	Clear communication
6	Building partnership/sharing power
7	Demonstrating honesty/respect for the patient
8	Predisposing factors
9	Structural/ Staffing

Thom and Campbell (1997:173-174)

A physician's ability to thoroughly evaluate patients' health problems, while providing appropriate treatment, was grouped under the umbrella of *technical competence*. The rest, except for the *predisposing factors* and *staffing*, were grouped under the theme of *physicians' interpersonal skills*. Although Thom and Campbell's study (1997) suffered from several limitations, since they attempted to study a broad topic making use of a small number of focus groups with mixed cultural and racial background, it was the first one that provided insights into the process of trust building. Moreover, it contributed to the literature by suggesting ways in which physicians could improve their effectiveness in terms of building and maintaining trust.

Hall *et al.* (2002:1422) broke down *general physician trust* into five domains:

Fidelity	caring and advocating for the patient's interests or welfare and avoiding conflicts of interest
Competence	having good practice and interpersonal skills, making correct decisions, and avoiding mistakes
Honesty	telling the truth and avoiding intentional falsehoods
Confidentiality	proper use of sensitive information
Global trust	the irreducible 'soul' of trust, or aspects that combine elements from some or all of the separate dimensions'

Hall *et al.* (2002:1422)

However, this definition of trust in the medical setting gives a general break down of the concept of trust in physicians, rather the patients' trust in a specific doctor, such as his/ her family or private doctor, which would be better described by *interpersonal trust*. Hall *et al.* (2002) perceived such general trust and interpersonal trust as being communicating vessels; general trust (i.e., trust in doctors in general), in particular, is somehow determined by patients' previous experiences with their personal physicians (interpersonal trust). Moreover, Hall *et al.* (2002) noted that patients who demonstrate higher levels of general trust in

physicians as representatives of the medical profession are expected to trust in individual physicians they meet for first time more readily.

Though this section is dedicated to examining how trust is understood in the medical context, it is worth mentioning Giddens' (1990) association between trust in *abstract systems* and trust in the operators of such abstract systems.

“Although everyone is aware that the real repository of trust is in the abstract system, rather than the individuals who in specific contexts ‘represent’ it, access points² carry a reminder that it is the flesh-and-blood people (who are potentially fallible) who are its operators.”
(Giddens, 1990:85)

Extending Giddens' (1990) perceptions about the association of *trust in abstract systems* and *trust in a physician* as a person in the healthcare setting, we could say that, although it is well-known that the actual repository of medical trust is in the health system, rather than in individual doctors who act as its representatives, access points carry a reminder that it is the flesh-and-blood people, i.e. doctors, who are its operators. Consequently, general trust in physicians is interwoven with interpersonal trust.

Additionally, Hillen *et al* (2011) found that “cancer patients’ trust appeared to be enhanced by the doctor’s perceived technical competence, honesty and patient-centred behaviour” (p. 227). Hillen *et al* (2011) verified, to an extent, previous findings that patients trust doctors with whom they have built a long-term relationship and who spend sufficient time not only to consult, inform and listen to their patients, but also to express their own empathy. Thus, we could say that Hillen *et al* (2011) revealed the multi-dimensional nature of trust, verifying previous definitions of trust in the patient-doctor setting (Thom and Campbell; 1997, Pearson *et al.*; 2000, Hall *et al.*; 2002).

Trust has also been found to be the very nature of both western and traditional medicine (Toafa *et al.*, 1999).

² Giddens defines as access points the meeting ground between the systems of modern societies and the individuals who represent those systems.

“There is the belief and trust in the healer acting as a vessel for this power. There is the belief and trust in the power of spiritual healing [...] and trust in the healer by the patient” (page number not available).

Valuable definitions and conceptions of trust can be found in the field of *nursing*, where the patient-nurse relationship is closely examined.

2.5.2 Defining trust in the patient-nurse relationship

Shea and Effken (2008) emphasise physical touch and face-to-face encounters as a crucial element of trust development between the patient and the nurse. Facial expressions, physical presence and body language have the potential to transfer empathy and compassion to the patient, supporting and promoting trust in the healthcare provider. Finally, the authors conclude that demonstrating ability, integrity and benevolence are necessary for building a trust-based relationship with nurses' patients. It is very important to report that *ability integrity* and *benevolence* are assessed both by scholars discussing nursing (Shea and Effken, 2008) and in organisational studies (Mayer *et al*, 1995) as integral parts of trust. That conclusion could probably serve as proof that it is an imperative need to explore the mechanics of trust per context rather than striving to come up with a commonly acceptable definition of trust.

Additionally, according to a review of literature conducted by Shea and Effken (2008), nurses' behaviour, associated with increased trust, includes the following six elements:

1	Mutual understanding
2	Clear communication
3	History of trust
4	Balance in power between the trustor and the trustee
5	Acceptance of personal disclosures
6	Expectations for the development of a long-term relationship

(Shea and Effken, 2008:136)

Dinç and Gastmans (2012), after conducting extensive research on definitional issues of trust in the nursing setting, concluded that

“...trust is considered as a process, and time, reliance on others, risk and fragility are identified as basic attributes of trust” (p. 223)

They also emphasised the imbalance of power between the trustor (patient) and the trustee (nurse), which increases as the vulnerability and dependency of the trustor increases. Following Dinç and Gastmans rationale, the more severe a disease, the more dependent a patient feels. In other words, Dinç and Gastmans imply that the levels of dependency vary according to the severity of the illness and, thus, different levels of trust occur.

Washington (1990) from the field of nursing, suggested that

“...trust is the reliance on the promise, written or verbal, of an individual,” (cited in Dinç and Gastmans, 2012:226)

while Hams (1997) defined trust as the

“willingness to engage oneself in a relationship that has reliance on either person (s) or thing (s), with an expectation that vulnerability may arise from either the trustee’s or truster’s performance” (Hams, 1997:353)

Hams (1997) implied the aspect of *mutuality* in the patient-nurse trust-based relationship. Similarly, Peter and Watt-Watson (2002) supported that pain is the result of a nurse’s distrust in the patient, which again implies the aspect of mutuality. The aspect of mutuality in that trust-based relationship has rarely been found in the nurse-patient and doctor-patient relationship literature. However, Hams (1997), among other ‘trust’ scholars, emphasised the aspect of *abilities* or *competence*.

Peter’s and Morgan’s (2001) adopt Baier’s (1986) definition, according to which, trust

“...is reliance on others' competence and willingness to look after, rather than harm, things one cares about which are entrusted to their care,” (Baier’s, 1986:259)

while they emphasise elements such as *competence*, *good will* and *affection*, which have also been found in the medical literature. Hupcey *et al.* (2001) perceived trust as an element that emerges when an individual identifies a need that cannot be satisfied in the absence of the contribution and risk-assessment made by a second person. According to Hupcey *et al.* (2001) trust is defined as

“...a willing dependency on another's actions, but it is limited to the area of need and is subject to overt and covert testing. The outcome of trust is an evaluation of the congruence between expectations of the trusted person and actions.” (Hupcey, 2001:290)

Carter (2009) defined trust as a state of

“...reliance on others’ competence and willingness to look after the things that one cares about, which are entrusted to their care, rather than to harm them.” (Carter, 2009, cited in Dinç and Gastmans, 2012:229)

At this point it is worth noting that the value of *clear communication* is highly appreciated in the patient-healthcare expert trust-based relationship (Shea and Effken, 2008; Thom and Campbell, 1997). Similar to Thom and Campbell (1997) and Shea and Effken (2008), Ong *et al.* (1995) emphasised the effect of a physician’s good communicational skills on the patient’s level of satisfaction, adherence to treatment and health outcomes, as well as the patient’s ability to recall and understand information. To the best of my knowledge, not enough research work has been published about the contribution of the patient as the second party in a remote session in terms of communicational skills. I would consider this research gap as a major parameter, particularly in our era, when “[...] information exchanges are increasingly electronic, while fewer face-to-face interactions make communication even more challenging” (Palmieri and Stern, 2009:163).

2.5.3 Misconceptions of trust in the medical setting

Misconceptions of trust are also encountered in the patient-doctor literature. In particular, trust is often confused in medical literature with terms such as the *therapeutic* or *working alliance*, *distrust*, *confidence* and *satisfaction*.

Although the *therapeutic alliance* (*working alliance*) is a term often used in the MHE-client relationship and closely related to trust, these two terms should not be confused. The former, which is additional to trust, refers to the element of mutual commitment about goals (Hillen *et al.*, 2002).

Moreover, *trust* and *distrust* should also be considered not as opposites, but as separate terms. In sharp contrast to trust, distrust refers to the expectation of adverse outcomes and behaviours. Thus, distrust should be separated from low trust, since the former term in contrast to the latter, refers to the absence of any possible positive expectation or outcome (Hillen *et al.*, 2002).

Trust, in the patient-physician relationship, should not be confused with *confidence*, since an individual in the state of confidence does not consider any alternatives as opposed to an individual in a state of trust, who has consciously decided to undertake a level of risk. Consequently, it could be supported that the element of *risk* is what distinguishes trust from *confidence*.

Finally, it is emphasised that *satisfaction* is far different from trust, since the former is retrospective, based on past experience, while trust implies the projection of positive future expectations. Hall *et al.* (2002) pointed out that:

“...while satisfaction is undeniably an important attribute and is related to trust, trust is a distinct attribute and may prove to be a fundamental force in shaping other attitudes, behaviors and outcomes” (p. 1432)

2.5.4 The carer-physician relationship: a trust-based one?

“Please understand that we often have to do with older people who have dementia either incipient or fully-blown. That is where the relative needs to be reliable, as it is him or her that transmits the information.” (Diab1)

It is a fact that healthcare professionals often face cases in which direct communication with their patients is not feasible, because, for various reasons, they are not capable of

communicating. For instance, infants and 1-3 y/o children, coma patients or elderly people suffering from dementia or Alzheimer's disease, are some of the cases where interactive communication between healthcare professionals and patients is impossible. Since 2004, when Wassmer *et al.* identified the research gap in the parent-paediatrician relationship, the carer-physician relationship has remained unexplored.

This research gap appeared in the course of my data-collection stage as a significant challenge that finally affected the latest version of my interview guide. In more detail, while interviewing paediatricians, I realised that there are groups of healthcare experts who have no experience of interactive communication and, hence, no experience of remote communication with their actual patients (i.e., infants). Instead, their entire experience concerned communication with their patients' carers. That realisation activated several key-questions, such as *"how could these sets of data contribute to answering my research question?"* given that my research interest concerns the patient-to-physician rather than the carer-to-physician relationship. One of the first thoughts that emerged for the resolution of such a complex issue was to omit that group of healthcare experts and focus on those whose professional communication was exclusively with their patients without the mediation of any third party. However, that idea could eventually prove costly, in terms of *time*, given that one of the hardest tasks during my PhD was recruiting interviewees. The limited yet available carer-physician literature review, as well as primary data found in my interviews, offered subtle indications that the carer-physician relationship bears close resemblance to that of patient-physician.

Cahill and Papageorgiou (2007) found that, even in cases where the children are between 6-12 years old and, thus, capable of being more interactive, they still have little involvement during consultations. In such cases, caregivers, who advocate for the patients they are taking care of, are present.

"...in clinical examinations at my office, you know ... you deal with infants or small kids. Until the kids become two years old or older, they can't tell you anything and so you rely on what's being told by the people looking after them." (Pedia1)

As Randall *et al.* (1999) noted “family members [...] together with professionals, they are carers of the patient” (Randal *et al.*, 1999, pg. 52). A *caregiver* may have either a *formal* or an *informal* status. A *formal* caregiver might be a nurse, a physician or a social worker, while an *informal* caregiver might be a patient’s family member, relative, friend, neighbour or member of a volunteer organisation. The significant distinction between formal and informal caregivers is that the latter are not paid for their services, whereas the former are.

In cases where parents are the only informal caregivers, it is widely accepted that they should have the right to make decisions on behalf of their children, based on the assumptions that (a) infants and children are not competent to make healthcare decisions on their own and that (b) *a priori* parents are expected to decide in accordance with their children’s best interest. However, I considered that it would be a risky theoretical leap to assume that the parent-to-physician relationship is by default a trust-based relationship, either because parents are expected to decide for their children best interest or because the parent, in a way, replaces their child as a communicator of data.

Answers regarding the nature of the *parent-to-paediatrician* relationship were initially sought in the limited paediatrician-parent literature review. According to Korsch *et al.* (1968):

“In pediatrics, patient refers to the patient’s parent, most commonly to the mother. Hence the patient and parent will be referred to interchangeably” (p. 865)

So, if we consider the patient-to-physician relationship a trust-based relationship by default, then it is logically deduced that the parent-to-physician relationship is also one based on trust.

Limited knowledge regarding the nature of the *parent-to-physician* relationship also comes from the field of palliative care ethics, where Randall *et al.* (1999) supported that

“... parents are rightly granted decision-making authority for their young children. Therefore, when the healthcare team offer treatment for their child, parents may accept or decline it. In this respect, the

parent-professional relationship bears a close resemblance to the patient-professional carer³ relationship ...” (p. 61)

Therefore, if we accept the thesis by Randal *et al* thesis that ‘*trust on behalf of the patient is an ineradicable feature of the relationship*’ (Randall *et al.*, 1999:50), it is logically deduced that the parent-to-physician relationship is one based on trust, too.

At a later point in time, Randal *et al.* (1999) underlined that *trust* is the indisputable element of the relative-to-physician relationship:

“...relatives must be able to trust that professionals are committed to the patient’s welfare. They must also be able to trust in the honesty and integrity of professionals, and any attempts by professionals to mislead relatives or patients undermine that essential trust” (p. 77)

Furthermore, data emerging from my own interviews indicate that both healthcare experts dealing with parents (Pedia1 and Pedia2) had already made their view on this issue clear. Specifically, both paediatricians had clearly stated that a trust-based relationship with parents is considered to be a prerequisite condition for establishing a trust-based relationship with infants and kids.

“A proper relationship between child and doctor cannot exist without the parents’ trust. Such a relationship will end soon. Something wrong is about to happen” (Pedia1)

“The paediatrician should win over both children and parents, which means that communication is extremely important in both directions. If you fail towards one direction, it is very likely that this relationship will not flourish in the future. It will end!” (Pedia2)

As has been explicitly demonstrated, the parent-to-physician relationship has been found to be a significant theoretical and methodological challenge. It was clear that the key question was whether the parent-to-paediatrician relationship is a trust-based one. In cases in which the parent-to-paediatrician relationship was found to be a trust-based one, it was possible to overcome the theoretical and methodological conundrum by expanding my research scope to

³ The term ‘carer’ for Randal *et al.* encompasses doctors, nurses and professional carers.

include the carer/parent-to-physician relationship. On the contrary, if this relationship was found not to be founded on trust, then my research question and research scope would be left untouched.

Finally, my research question became:

“How do self-employed healthcare experts experience remote communication with both their patients and their patients’ carers - through the lens of trust-, via ICT designed for commercial purposes?”

To sum up, though there are subtle indications from paediatrics, palliative care literature and my own data that the carer-physician relationship is one founded in trust, there is still a significant research gap to be bridged. However, it is not only the carer-physician relationship that remains largely unexplored. Too little is also known about the *physician’s trust* in patients.

2.5.5 Mutual trust in the patient-physician relationship

Most of patient-physician literature adopts the approach only the patient’s trust matters that in a trust-based relationship. It is common knowledge that in the light of an illness, individuals find themselves in a vulnerable position, since their illness and lack of medical expertise lead them to trust the management and resolution of their health issue in the hands of third parties. In other words, placing the management and the treatment of their illness in a third party exposes them either to the risk of ineffective management, due to a physician’s low competence, or to the risk of being manipulated in financial, sexual or other terms. Consequently, what defines the patient-physician relationship is asymmetry in terms of knowledge, which is transformed to asymmetry in power. However, there are subtle, albeit limited indications, that the patient-physician relationship is one based on mutual trust.

As Calnan and Rowe (2006) supported,

“in contrast to the sizable literature assessing trust from the patient perspective studies examining either the value and impact of trust from the practitioner perspective and from a managerial or organizational perspective are very limited” (p. 532)

Similar results were reported in the past by Cook *et al.* (2004) who had found that

“there is also some awareness –although it is much less frequently mentioned- that behaviours serve as important clues for physician trust in a patient” (p. 90)

Additionally, Cook *et al.* (2004) recognised that there used to be a limited number of research papers that had attempted to explore and speak about the reciprocal nature of the patient-physician trust. In particular, one of the first papers that implied the aspect of mutuality in the patient-doctor relationship was that by Thorne and Robinson (1988) who made use of the term *reciprocal trust*. Furthermore, they regarded it “as a necessary component of satisfying, effective healthcare relationships, when the illness is of an ongoing nature.” (Thorne and Robinson, 1988:782) Irwin *et al.* (1989) stressed that

“...clinical medicine is above all else about communication between two people, it is about establishing an effective working relationship in which there is mutual trust.” (p. 387)

Roter and Hall (1992), emphasised the functional role of mutuality in the patient-physician relationship underlying that

“Each of the participants brings strengths and resources to the relationship, as well as a commitment to work without disagreements in a mutually respectful manner.” (p. 35)

Similar indications are offered by Miller (2007) who supports that “physician-patient trust means trust in the patient, too” (p. 52)

Rogers (2002) indicated there is a lot of work to be done on under-researched aspects of the patient-physician relationship such as the latter’s trust in their patients or lack thereof. He made use of the concept of the *trustworthy patient*, while supporting that it is important for doctors, in regard to ethos, to trust patients. Rogers (2002), in his discussion paper, described the trustworthy patient as an individual who demonstrates integrity, i.e., who has no intention of manipulating physicians with false information about their medical history, as well as someone who possesses a certain level of competence. However, no detailed description of the trustworthy patient was provided.

Merrill *et al.* (2002) reported the physicians’ fear of being deceived by drug-using patients,

implying the existence of a mutual, rather than a one-way, trust-based relationship. In my interpretation, the reference made to the concept of the potentially deceitful patient by Merrill *et al.* (2002), also implied the existence of a trustworthy patient about whom too little is known.

Bültzingslöwen *et al.* (2005) found that “patients felt it important [...] to be believed and taken seriously” (p. 215). Although Bültzingslöwen *et al.* (2005) do not shed adequate light on that particular code, i.e., “to be believed and taken seriously” (p. 215), they do imply that there are patients whom doctors do not believe and, thus, are considered as untrustworthy.

Similar results reported by Jain *et al.* (2006) expressed concerns about the accuracy of intravenous drug-users’ self-reports. They reported that a number of reasons cause drug-users to misreport data regarding their drug use, such as the type, duration and quantity of drug use. However, the authors highlighted that physicians would make decisions based on these reports and, thus, it was extremely important to have accurate information. Among the reasons that could offer explanations about misreporting was the drug-users’ intention to minimise their drug use in order to prevent being isolated from their families and society. The authors also emphasised that over-reporting, as well as under-reporting, by patients is not a rare phenomenon, especially where opiate use is involved, and, therefore, physicians are urged to be aware of such a contingency.

Thom *et al.* (2011) were the first to attempt to develop and validate a scale of physicians’ trust in their patients. In more detail, they built a model based on qualitative data collected via focus groups and interviews with physicians. According to Thom *et al.* (2011) *trustworthy patients* (a) provides accurate as well as complete histories, (b) asks questions, (c) adhere to plans of treatment, and (d) follow up while demonstrating respect of the physician’s time and personal boundaries. Finally, the trustworthy patient is an individual who demonstrates integrity in approaching physicians with no secret agenda, i.e., what Mayer *et al.* used to call an ‘egocentric profit motive’ (p. 718).

Subtle indications of a mutual trust-based patient-healthcare relationship come from the field of *nursing*. Specifically, Hams (1997) defined trust as the “willingness to engage oneself in a relationship that has reliance on either person (s) or thing (s), with an expectation that

vulnerability may arise from either the trustee's or trustors' performance" (p. 353), implying a bidirectional trust-based relationship. Similarly, Peter and Watt-Watson (2002) supported that the result of nurse's distrust in the patient are elevated pain-levels, implying again the lack of mutuality in terms of trust.

To sum up, it is apparent that too little is known about physicians' trust in patients as compared to patients' trust in their doctors. Though a limited number of studies implies that the patient-healthcare expert relationship is grounded in mutual trust and respect, there is not adequate knowledge about the *trustworthy patient's* profile in terms of either personal qualities (integrity, etc.) or skills (competence, etc.).

2.6 Summary

It is generally accepted that the patient-to-physician relationship is one based on trust, since the trustors called patients find themselves in a vulnerable position in the light of a severe or possibly severe health issue, which they cannot treat or manage on their own. In other words, patients place the fate of their health, not to mention their lives, in a trustee called physician, who claims to have expertise, which, in other words, is not in the patients' control. In brief, patients grant physicians "discretionary powers, which include the power to help or harm" (Rogers, 2002:77) them. In the light of a serious health issue, such asymmetry in terms of expertise is transformed into power asymmetry.

Moreover, a number of research gaps and unexplored aspects of the patient-healthcare expert relationship have been identified, such as the carer-physician relationship. It has become clear that too little is known about the *carer-physician relationship*, though there are plenty of cases where doctors do not directly communicate with their patients but, instead, with their patients' carers, be they formal or informal ones. Moreover, not enough research work has been published about the contribution of the patient, as the second party in a remote session, in terms of communicational skills. Additionally, too little is known about the *doctor's trust* in the patient, which is in sharp contrast to our knowledge with regard to the *patient's trust* in the physician. Although there are a few papers that imply the existence of a *trustworthy patient*, they do not offer a detailed picture of his/her qualities, thus, masking the aspect of a *mutual* as opposed to a one-way trust-based relationship.

Chapter 3

The Contemporary Sociological Landscape of Telemedicine

Chapter three has been designed to place the current doctoral thesis within the broader sociological discussion regarding the digital transformation taking place in the health sector from a power, risk, skills and, finally, trust perspective. Chapter three begins with a brief historical background regarding the evolution of the patient-physician relationship from a power balance perspective, and the major transformations taking place in recent years due to ICT invasion in the health sector. Moreover, the current chapter also provides a brief description regarding changes in *patients' work* due to the invasion of ICTs in their daily routine, followed by a critical approach of the new patient-physician relationship in terms of power balance through the lens of trust and skills. Special reference is made to the human senses as an epistemological tool for healthcare experts. Chapter three ends with an attempt to place the current PhD thesis within the contemporary landscape of Beck's *risk society*.

3.1 The role of patient in the digital health era: from *paternalism* to *patient empowerment*

What dominates the classical patient-doctor relationship literature is the element of power imbalance between them as a result of their knowledge asymmetry. However, there has never been a single perspective about how these power imbalances should be incorporated by doctors at the stage of their decision-making process. On the one extreme, we have the old-school perspective of *paternalism* i.e. “[t]he interference with a person's liberty of action, justified by reasons referring exclusively to the welfare, good, happiness, needs, interest or values of the person being coerced” (Dworkin, 1972, cited in McKinstry, 1992:340). Similar to *paternalistic* doctors, the *autocratic* ones find themselves being in a superior position without seriously taking into consideration patients' opinions (McKinstry, 1992:340). On the other extreme, we have the *informed-decision-making model*, according to which patients are approached as consumers, rather than as lay persons, ready to decide for themselves about their treatment plan, based on information and options provided by healthcare experts who act as agents. Finally, in the stretch between these two extreme approaches there are a number of alternative perspectives, such as that of *shared-decision-making*.

Consumerist and health activist movements, such as socialism and feminism, calling for democratisation in healthcare services, have contributed to that major shift from paternalism to more collaborative models (Lupton, 2013; Goodyear-Smith and Buetow, 2001). Lupton (2013), among other scholars, attributed the shift to the emerging request for democratisation in healthcare, i.e. those voices calling for patients to become more active participants with medical and healthcare issues without taking doctors' decisions for granted. Terms such as the *expert patient*, *patient empowerment*, *patient activation*, *patient engagement* or *patient work*, which are briefly described within the current section, reflect the transformation perceived, or the need for transforming patients from passive recipients of their doctors' decisions to active participants who can effectively manage their own healthcare.

A key indication of such a shift is reflected in the report produced in 2001 by the British Department of Health and referring to the *expert patient*. According to this report, patients:

“[c]an become key decision makers in the treatment process. By ensuring that knowledge of their condition is developed to a point where they are empowered to take some responsibility for its management and work in partnership with their health and social care providers, patients can be given greater control over their lives. Self-management programmes can be specifically designed to reduce the severity of symptoms and improve confidence, resourcefulness and self-efficacy.” (Department of Health, 2001, cited in Tattersall, 2002:227)

In my interpretation, it is apparent that British policy makers urged that patients could be treated as “key decision-makers” in the healing process itself, rather than as laypersons who should uncritically assimilate and apply doctors' decisions. Moreover, the policy implied that such a form of empowerment, i.e. *patient empowerment*, results in shared responsibility with doctors and the wider healthcare personnel in charge. Finally, British policy makers anticipate that patients' empowerment will have a positive effect in terms of both patient welfare and public finance. According to Tattersall (2002), the vision of policy makers “suggests a violent swing from the bad old days, when patients were passive consumers, to a new Utopia in which empowered patients will reap benefits” (Tattersall, 2002:227).

The report produced by the British Department of Health, among other government reports and research works in the broader field of medical sociology, makes extensive use of the patient empowerment concept. According to Tones and Tilford (2001), *individual or self-empowerment* in the health context is defined as “a set of competences and capabilities which, together with certain related personality characteristics, contribute to a relatively high degree of actual control over a given individual’s life and health” (p. 40). Similarly, Calvillo *et al.* (2015) provide a definition of the *patient’s empowerment* concept making use of the same key-terms that Tones and Tilford also used, i.e. capabilities and an active role. In particular, Calvillo *et al.* (2015) approach patients’ empowerment as a concept “that covers situations where citizens are encouraged to take an active role in the management of their own health, transforming the traditional patient-doctor relationship and providing citizens with real management capabilities” (p. 644). Similar to the report produced by the British Department of Health, the European Commission’s defines *patient empowerment* as a “process to help people gain control, which includes people taking the initiative, solving problems, and taking decisions, and can be applied to different settings in health and social care, and self-management”. It is highlighted that according to the European Commission (2012) report patient empowerment along with digital health literacy are considered as essential elements for the successful deployment of eHealth policies. Overall, the emergence of the concept of *patient empowerment* echoes the voices of healthcare professionals, policy makers, healthcare and patient organizations calling for “the patient to take more control in the medical encounter as well as when dealing with health challenges” (Andreassen and Trondsen, 2010). Terms such as the *patient empowerment* and *expert patient* are signalling the transition from the rather old-school approach of paternalism in the patient-doctor relationship towards much more collaborative ones.

Besides the impact of social movements, it is often supported that patients’ transformation to active, empowered or even engaged participants in the healing process is also due to advances in information technologies, which is the core of the current PhD thesis (Oudshoorn, 2008; Lupton, 2013; Wright, 2011; Rogers *et al.*, 2011; Swan, 2012). It was Wright (2011) who emphatically stated that “[h]ealth information technologies also appear to be making it easier for both regulators and consumers to take control over medical care away from physicians and other health care providers”. In the age of paternalism doctors, among other limited sources,

such as magazines, newspapers, radio shows etc., were the only source of information for patients seeking treatment. In our digital health era, when Web 2.0, Web 3.0 and Internet of Things (IoT) technologies thrive, the patient has instant access to a broad, as well as deep, pool of alternative sources of information. That pool is comprised of data coming either from the web, such as health-organisations websites, medical journals, video tutorials and lectures uploaded on YouTube, or even from their own bodies. For example, wearable devices such as smartphones or smart watches, offer patients instant access to and accurate measurements of their personal basic health sign measurements (body mass index, heart rate, blood pressure, etc.). To sum up, there are indications that ICT advances “have broken doctors’ monopoly on technical and research knowledge” (Goodyear-Smith and Buetow, 2001).

To sum up, it should not be considered a matter of chance that terms referring to the active role of the patient are frequently encountered in the discourse about the patient’s role in the age of self-care and self-monitoring via ICT. As demonstrated in the following sub-section, self-care and self-monitoring technologies demand that patients should undertake tasks that used to be exclusively undertaken by healthcare professionals. Rogers *et al.* (2011) note that “as professional work becomes more protocol based, so too does the ‘work’ of patients” (p. 1078). The patient’s work expected to lead to the desirable level of empowerment demands a particular set of competences and capabilities, as Tones and Tilford (2001) have concluded. Nowadays, ICT offers patients the potential to become active participants in the healing and caring process. In other words, the *digitally engaged patient* – a term coined by Lupton (2013) - is placed “at the centre of action-taking in relation to health and healthcare” (Swan, 2012, p. 97) in sharp contrast to the age of paternalism.

3.2 From patient work to invisible and sensory work of the digitally engaged patient

The concept of *patient work* refers to “practices in everyday life and their expression in different patterns of social life” (Rogers *et al.*, 2011, p. 1078). Although it is a term often encountered in digital health literature, it is worth mentioning that it existed earlier; it was coined by Corbin and Strauss (1988) and referred to three kinds of work undertaken by patients suffering from chronic illnesses: “illness work (concerned with symptom management); everyday life work (concerned with practical tasks, such as housework, caring, and paid

employment) and biographical work (concerned with the reconstruction of the ill person's biography)" (Rogers *et al.*, 2011, p. 1078). The question emerging at this point is "what is the patient work in the age of telemedicine, self-care and self-monitoring via ICT"?

According to relevant literature studying patients' interaction with home-based ICT for self-monitoring and self-caring purposes, patients should execute a number of tasks with discipline and accuracy. For example, Oudshoorn (2008) has spoken of the *invisible work* produced by patients who are suffering from critical heart problems and monitor themselves via an ambulatory ECG recorder in the light of their symptoms. In response to their daily tasks, patients are expected not only to have the skills to recognise the symptoms, but also to activate the ECG, record them into the device and, finally, contact a specialised medical centre themselves. In brief, it is of high value for patients to have the skills to 'scan' their own bodies with accuracy so as to transmit reliable data to their healthcare professionals. Scanning as part of a patient's tasks has been defined by Lupton and Maslen (2017) as *sensory work*, while the patient who "takes up the new digital media technologies to engage in self-monitoring and self-care" is often called either the *digitally engaged patient* (Lupton, 2013) or the *future patient* (Finch *et al.*, 2008).

Such types of work reveal that, in the age of digital health, patients have been assigned tasks and, thus, roles, which in the past were the exclusive responsibility of healthcare experts (Oudshoorn, 2008). As Rogers *et al.* (2011) support, "aspects of patients' use of telehealth and telecare can be seen as professionally delegated work", since they actively involve themselves in "diagnostic socio-technical work of home-care professional nurses and physicians" (p. 1077) verifying Illitch's theory. It should be noted that in 1981, it was Illitch who stressed that "work does not disappear with technological aid. Rather, it is displaced sometimes onto the machine, as often onto workers" (cited in Oudshoorn, 2008, p. 272).

To sum up, the infusion of ICT in patients' daily routines has turned them to active participants who have work to do. As it is briefly described below, it is expected that the adoption of ICTs in the patient-healthcare expert communication can't be sustainable without patients' contribution in terms of work and, therefore, skills.

3.3 A trust-oriented approach of *patient work*

The current sub-section approaches patients' work in the light of remote interaction with their healthcare experts from a skill-set and risk perspective that involves the core elements of trust. A limited number of research papers regarding the patient-healthcare expert remote interaction via telecare and telemonitoring systems have expressed concerns about risks associated with a variety of patients' skills (Mort *et al.*, 2003; Oudshoorn, 2008; Oudshoorn, 2009; Lupton, 2013; Lupton and Maslen, 2017; Pettinari and Jessopp, 2001; Wahlberg *et al.*, 2003;). Based on research work available, it is concluded that the lack of physical proximity, in the light of the patient-healthcare expert remote interaction, generates an asymmetry in terms of data possession, which, in turn, may lead to the risk of misdiagnosis. It is expected that patients' contribution in terms of skills seems to be vital for mitigating such risks in an effective manner.

Physical proximity refers to nearness within which healthcare staff physically touch and care for patients' bodies" (Malone, 2003:2318 cited in Oudshoorn, 2008). As clearly demonstrated in paragraph 2.5.2 expressions of physical proximity, such as touch, may demonstrate and transfer empathy on the part of the healthcare staff. Additionally, human senses, such as hearing, vision or smell, which are still considered as precious means for medical data collection by healthcare experts, demand physical proximity, too. It is the physical proximity that allows hand-on techniques, such as palpitation, to take place. Although the contribution of palpitation in medical science cannot be challenged, technological developments have favoured sensory generation of body data and, consequently, medical knowledge, too. For instance, old school medical tools, such as the stethoscope or X-rays - what Nettleton (2004) has defined as *mechanical medicine* (p. 667) - are still applied in the clinical examination process. Although such medical tools interfaced between doctors' hands and patients' bodies, they demanded physical proximity, too. To sum up, the aspect of physical proximity is interwoven with the classical practice of medicine for a long period of time.

The absence of physical proximity is the key-difference between *mechanical medicine* and the wider spectrum of telemedicine technologies. In the age of *informational medicine* (Nettleton, 2004) or *informatized medicine* (Mort and Smith, 2009), what has been mediated between the patient and the healthcare expert is distance itself. Although ICT offers the opportunity for

both *remote doctors* and *absent patients* (Mort et al., 2003) to meet each other in a real-time shared virtual space, they are finally found spatially distanced. It has been observed that the absence of physical proximity may create a sense of uncertainty to the healthcare staff in charge, due to the incompleteness of medical data (Mort and Smith, 2009). With regard to the risks associated with practising medicine in the absence of patients' physical bodies, Mort and Smith (2009) highlighted that "the risk of devaluing the experiential, haptic and affective knowledge of both apprentices and practitioners" (p. 215) is always present. As Mort *et al.* (2003) supported, on the one hand, certain types of data are gained via ICT, but, on the other hand, other types are lost.

For example, it has been found that tele-dermatologists asked to give image-based diagnoses expressed concerns about their accuracy, due to the limited volume of data available (Mort *et al.*, 2003). In particular, they highlighted that an image-based diagnosis makes a wider group of data, such as patients' personal experience or skin texture, inaccessible to them. As one of the interviewees mentioned:

"[w]as that amount of information you actually physically had to make the diagnosis sufficient without bringing the patient in? And probably misdiagnosis could be slightly higher" (Mort *et al.*, 2003:288)

What is worth noticing here is that, though visual examination in dermatology is privileged, tele-dermatologists expressed concerns with regard to the validity of their diagnoses. In other words, they felt that digital images, as a representation of an actual medical case, were not adequate to speak for the patient across space and time (Mort and Smith, 2009). Similar to Mort *et al.* (2003), Lupton (2013) underlined that healthcare experts working on telemedicine systems often make their decisions based on "conflicting heterogeneous streams of incomplete data" (p. 265). It is common sense that, though it is part of patients' work to collect and share the necessary medical data from their own bodies, it is the healthcare experts who are the users of such medical information (Lupton, 2003; Mort and Smith, 2009). To sum up, the absence of physical proximity could lead to higher risk of misdiagnosis, if not to a stream of legal risks, such as malpractice lawsuits.

Similar findings have been reported by studies exploring synchronous remote communication between patients and healthcare experts working through nurse telephone triage services. It

is common sense that tele-nursing staff have no visual, tactile or olfactory sense of the patient. Consequently, tele-nurses have no other option than to focus on (a) sound data that phone devices may afford (breathing rate, intonation, etc.) and (b) patients' descriptions. Shah *et al.* (2013) found that making any recommendations to older people with regard to health issues over the phone may jeopardize effective decision-making on behalf of the health expert due to misreporting on behalf of the patient. That risk is particularly increased in non-medical settings, where carers, such as family members, lack the training and, thus, the skills to report an accurate and complete patient history (Shah *et al.*, 2013). As Pettinari and Jessopp (2001) denoted on their study about nurses' experience in NHS Direct service, "nurses' ears become their eyes". Similar views were reported by nurses working at tele-nursing call centres (Roing *et al.*, 2013; Derkx *et al.*, 2009). A tele-nurse interviewed by Roing *et al.* (2013) reported that she feels:

"[...] unsure about how far to go when asking certain patients about their problems, or maybe not going deep enough with others. That's what I think. Did I cover everything? Am I doing the right thing? Could I have asked more?" (Roing *et al.*, 2013:4)

However, relying on patients' descriptions bears even fatal health risks for patients and legal risks for nursing staff. Roing *et al.* (2013) reported that the patient's psychological state during the phone-call affects not only the quantity of data that the patient or carer is able to absorb, but, moreover, it affects the way both patients and carers describe the actual events or data (symptoms). Roing *et al.* (2013) placed emphasis on the patient's speaking skills, reporting that communication by phone becomes challenging, particularly in cases when the patient is not a native speaker.

Furthermore, Wahlberg *et al.* (2003), who studied the caller/patient and tele-nurse interaction, found that "not seeing the patient" was rated as one of the most important challenges they were facing in their daily routines as professionals. Wahlberg *et al.* (2003), similar to Roing *et al.* (2013) and Pettinari and Jessopp (2001), found that the absence of physical proximity made the staff depend on callers' descriptions. Risks associated with lack of physical proximity were also mentioned by Whalen *et al.* (1988), who demonstrated that, in the light of a "call for help" to an emergency service agency, "words can fail". In particular, they demonstrated through a

single case analysis the fatal outcome of such a phone call, during which the caller failed to describe significant symptoms to the tele-nurse due to a dispute between them.

To sum up, Mort and Smith's (2009) claims that "[t]he distance or space opened up by telemedicine became filled with heterogeneous" (p. 224) knowledge and materials are verified. In my perspective, the absence of physical proximity creates a number of risks and, thus, raises a number of trust issues with regard to patients' skills. I hold the view that a skilful patient may contribute to the minimisation of such risks through their effective sensory and communication work. For example, in the case of the NHS Direct service, it is highly important that the patient calling possess the necessary skill-set (communicational, aptitude, stress-management, etc.) so that no critical health data are missed or misreported for any reason. Similarly, healthcare experts working over the cardiac telemonitoring system rely not only on data recorded by the patient on the ECG device, but also on data collected verbally, via interviews by patients in the aftermath of the event. Any interpretation or decision made is based on both pools of verbal (anamnesis) and non-verbal data recorded by the ECG. It is apparent that, in the absence of physical proximity, healthcare staff becomes more dependent on patients work and, thus, on the quality of each patient's skill-set. This is why Pettinari and Jessopp (2001) found that the lack of necessary skills required for communicating medical data (symptoms, events, etc.) with accuracy may affect patient's or *caller's credibility* and *trust* (Pettinari and Jessopp, 2001).

My trust-perspective meets that of Giddens' (1990), who has highlighted that in the "absence of time and space [...] the prime condition of requirements for trust is not lack of power but lack of full information" (p. 33). Quoting Giddens (1990):

"Trust is related to absence in time and in space. There would be no need to trust anyone whose activities were continually visible and whose thought processes were transparent, or to trust any system whose workings were wholly known and understood. It has been said that trust is "a device for coping with the freedom of others," but the prime condition of requirements for trust is not lack of power but lack of full information." (Giddens, 1990:33)

From a trust-perspective, it is patients' (communicational) skills and sensory work that are expected to bridge, or even mitigate, risks associated with the medical data asymmetry that

exists between them and the remote healthcare staff. There are subtle indications based on limited evidence provided by the wider telemedicine literature and Giddens' perspective, that, in the light of remote communication between experts and non-experts, information and, therefore, power is reallocated. Healthcare experts' power outflows become non-experts' (patients') power inflows, since the former have no direct tactile, visual, olfactory or audio sense of the latter at the same time in the same place. Nevertheless, there are still voices supporting that the redistribution of information will inevitably result in power redistributions (Gann, 1998; Finch *et al.*, 2008). Power redistributions in the remote communication setting are discussed in more detail in chapter 8.

3.4 The human senses perspective: a missed opportunity for the theorists of telemedicine

As demonstrated so far, remote healthcare experts have expressed concerns about the quality of their decision, particularly when these are made in absentia of a patient. Their scepticism lies in the assumption that remote diagnosis with (*see* tele-nursing services, ECG etc.) or without patients' intervention (*see* tele-dermatology) deprive healthcare experts of a rich pool of data (smell, touch, patients' experience, body language, etc.) that it is accessible only through the patient's own senses. Actually, what healthcare experts operating in remote challenge is the potential of ICT to render medical data collected in remote as sensible to healthcare experts as if these had been collected through the physician's own senses. Although respectful scholars have identified the risk of misdiagnosis in any kind of telemedicine (Mort *et al.*, 2003; Oudshoorn, 2008, 2009; Lupton, 2013), it was only Lupton (Lupton, 2017; Lupton and Maslen, 2017) who identified the overshadowed aspect of sensory dimensions in telemedicine. In particular, Lupton and Maslen (2017) underlined that "[b]ringing the sensory dimensions of medical work to the fore can help to identify and explain the complexities of why telemedicine initiatives are considered to succeed or fail" (Lupton and Maslen, 2017:1559). Within the current section, the human senses are approached from an epistemological perspective with special focus on the irreplaceable sense of touch. I conclude that, though there is a significant volume of knowledge in the field of philosophy, sensory studies and 3D technologies with regard to senses, as a tool for experiencing the world, telemedicine scholars have so far failed to bring that element to the fore of their research.

3.4.1 Senses as means for medical-data collection: an epistemological approach of the senses in medical practice

According to Crooke's (1615) controversial work titled *Mikrokosmographia*, human senses are defined as:

“a knowledge or discerning of the Object received formally in the Organ [...] in every Sense there be three things especially to be stood upon, the Object, the Medium and the Organ” (Crooke, 1615:653, 722 as cited in Mazzio, 2005:88)

Regardless of each individual's epistemology, human senses are the channels through which human beings experience the world in an either “accurate” or “distorted” manner. Although, as a theoretical opponent of realism, I share Nietzsche's criticism about “the eye outside of time and history”, I accept that senses can even be a “contaminated” channel through which we experience the world.

In the science of medicine, the senses are tools for collecting valuable optical, audio, haptic, and olfactory data. It should not be forgotten that sensory work has been “a mainstay of medical training, with textbooks detailing sensory cues of health and illness since the nineteenth century” (Van Drie, 2013, as cited in Lupton, 2017:1561). The use of human senses has been applied as a primary diagnostic tool by medical practitioners who lived in ancient Greece (see Hippocrates), India (see *Hindu* physicians), as well doctors who lived during the Middle Age and the Age of Renaissance (Nicolson, 2000). It should not be considered a matter of chance that, even in our contemporary era, when ICT in healthcare is thriving, there are still doctors who favour medical-data-collection via palpitation and other hands-on techniques. As Carmel (2013) has highlighted, even in intensive care units (ICU), where the presence of advanced medical technology is significant, palpitation and hands-on skills are highly valued, especially in cases when doctors feel they should not trust monitoring systems' indications. Even when patients are under general anaesthesia, it is still important for healthcare staff to be able to touch the patient (Mort and Smith, 2009). This is why the sense of touch in the medical practice is often considered primary. Moreover, Cartwright (2000) characterised palpitation a “cornerstone” (p. 351) of medical science. In the light of scepticism of healthcare experts operating in remote about the width and depth of the accessible spectrum of medical data, it is of high value to identify what makes touch different from any other sense.

For a group of philosophers and scholars, the sense of touch has always been considered superior to the rest of the senses. For example, Aristotle in his work *De Anima (On the Soul)* supported that no other sense can exist in the absence of touch. The same thesis has been supported by a number of modern scholars from the fields of the arts, social studies and philosophy. For example, Pallasmaa (2005), from the field of architecture, supported that “all the senses, including vision, are extensions of the tactile sense; the senses are specialisations of skin tissue, and all sensory experiences are modes of touching and, thus, related to tactility” (p. 10). Pallasmaa (2005), at a later point, mentioned that “[r]egardless of our prioritisation of the eye, visual observation is often confirmed by our touch” (p. 23). Montagu (1986), from the field of anthropology, has expressed the view, based on medical evidence, that touch is superior compared to the rest of the senses:

“[The skin] is the oldest and the most sensitive of our organs, our first medium of communication, and our most efficient protector ... Even the transparent cornea of the eye is overlain by a layer of modified skin. [...] Touch is the parent of our eyes, ears, nose, and mouth. It is the sense which became differentiated into the others, a fact that seems to be recognised in the age-old evaluation of touch as the ‘mother of the senses’.” (Montagu, 1986:6 as cited in Pallasmaa, 2005:11)

Even René Descartes (1596-1650), one of the mainstays of the Age of Enlightenment, who contested the human senses as an authoritative source of knowledge, equated touch with vision. It was Descartes who supported that touch is “more certain and less vulnerable to error than vision” (Levin, 1993:71).

3.4.2 Human senses: an overrated means in the digital era

Doubts against the value of the human senses as an accurate epistemological vehicle have been cast since the Age of Enlightenment. In particular, Giddens (1990), in his work *The Consequences of Modernity*, mentions that:

“[a]lthough most regarded the evidence of our senses as the most dependable information we can obtain, even the early Enlightenment thinkers were well aware that such ‘evidence’ is always in principle suspect. Sense data could never provide a wholly secure base for knowledge claims. Given the greater awareness today that sensory observation is permeated by theoretical categories, philosophical

thought has in the main veered quite sharply away from empiricism.”
(Giddens, 1990:49)

In the age of digital health, obsessive adherence to classical, rather than old-school medical practices, has not been left without criticism by scholars coming from different disciplines. For example, Majchrzak and Markus (2012) from the broader discipline of computer-mediated communications (CMC) have challenged the assumption encountered in the *information richness theory* (Daft and Langel, 1983) that face-to-face communication should be considered “the baseline against which all mediated communication seems impoverished or diminished in some way” (p.3). Quoting Majchrzak and Markus (2012),

“[t]his privileging of the “natural” ignores the possibility that humans using technology can often enact new practices or achieve outcomes that could not occur without the use of technology.” (p.3)

Similarly to Majchrzak and Markus (2012), Lupton (2013) has stressed the advantages of “digital” medical data as being far more objective and richer in terms of medical data when compared to those collected through the human senses. As Lupton (2013) stressed:

“Data, metrics and algorithms are represented as clean, contained and unemotional, far removed from the messy contingencies and uncertainties of the body and its ills and the distressing or unsettling emotions associated with these.” (p.266)

Lupton in her very recent work (Lupton, 2017; Lupton and Maslen, 2017) brings to the fore of telemedicine research the neglected element of sense. In particular, Lupton and Maslen (2017), through their literature review research, unravelled the role of the senses in telemedicine, in medical work and in biomedicine. What I would consider a breakthrough in Lupton’s (2017) work is her attempt to incorporate knowledge and experience regarding the role of human senses from the field of digital arts, three-dimensional and data-visualisation technologies to the field of telemedicine. For example, research from the field of data-visualisation technologies produced by wearable devices indicated that the data generated were often viewed as more “truthful” or “accurate” compared to haptic and other sensory input (Pink et al., 2017). Lupton (2017) has also drawn experience from the field of human-computer interaction (HCI), which has recently focused on possible ways in which data can be modified into three-dimensional, physical artefacts commonly known as “data

physicalisations” or “physical visualisations”. What telemedicine researchers could draw from the HCI research is that “multisensory experiences are richer and better understood than those that tend to emphasise only the visual dimension” (Lupton, 2017:7).

“[s]uch artefacts facilitate knowledge of data that otherwise would not be available using such features appealing to haptic sensations as texture, stiffness, temperature and weight (Alexander *et al.*, 2015; Jansen *et al.*, 2015; Stusak, 2015).” (Lupton, 2017:7)

In my perspective, the HCI literature should be thoroughly studied and incorporated by scholars exploring the remote patient-healthcare expert communication and collaboration (telemedicine). The research opportunity lying ahead is that scientists and digital artists could work towards the visual plus haptic representation of a patient’s body located in remote. It should not be forgotten that remote healthcare experts’ scepticism lies in the lack of multilevel access to a patient’s body in sensory terms. I would suggest that such a research opportunity should not be approached as a futurist’s utopian ambition. Besides, Lupton (2017) has already referred to a number of 3D visualisation projects accomplished by either artists or scientists, who have started to use “materialisations of data that invite haptic responses by rendering them into 3D forms” (p. 8), a work commonly known as “data sculptures”. If we adopt Aristotle’s epistemological proposition that no other sense can exist in the absence of touch, we may realise why it is of critical importance to develop haptic representations of an ill person’s body.

3.5 The patient-healthcare expert remote communication in a *risk society*

I would consider the study of the patient-doctor remote communication as detached from the bigger social picture, a limitation, not to mention a fallacy. The aim of this sub-chapter is to provide a brief background with key information on the broader social landscape in which major changes, such as the patient-doctor remote communication, take place. It is concluded that the substitution of traditional face-to-face patient-doctor communication with remote communication, is being implemented in our post-modern *risk societies* (Beck, 1992), which are characterised by lack of trust in professionals.

Sociologists often use the term *modernity* or *post-modernity* to identify the transition “from a system based upon the manufacture of material goods to one concerned more centrally with

information” (Giddens, 1990:2). *Information* itself appears to be the crucial element responsible for that major social shift, due to its capacity to *separate time and space* – often called by Giddens as *empty space*.

“[w]hat structures the locale is not simply that which is present on the scene; the visible form of the locale conceals the distanced relations which determine its nature.” (Giddens, 1990:19)

Beck and Giddens, among other respectful scholars from the field of sociology, have significantly contributed to the analysis and observation of the social shifts that have taken place in the transition to *modernity*. Both scholars agree that modern societies are governed by risks they themselves have produced. In particular, Giddens has (1991) stressed that

“to live in the universe of high modernity is to live in an environment of chance and risk” (Giddens, 1991:109)

Similarly to Giddens (1990), Beck (2006) has mentioned that

“modern society has become a risk society in the sense that it is increasingly occupied with debating, preventing and managing risks that it itself has produced” (p. 4).

Space and *time*, which used to coincide during the pre-modern era, now seem to be divorced in our post-modern societies, setting a new framework for human interaction. Contemporary working practices, such as telework, mobile work, telemedicine, telecare or e-therapy, are fruits of that new social shift that fosters ‘relations between *absent* others, locationally distant from any given situation of face to face interaction’ (Giddens, 1990:18). The “*lifting out* of social relationships from local contexts of interaction and their restructuring across indefinite spans of time-space” (Giddens, 1990:21) is defined by Giddens as *disembedding*.

Research findings from the field of the sociology of medicine and telemedicine seem to verify the very essence of Beck’s (2006) *risk society*. In particular, Mort *et al.* (2003) found that that dermatologists who were operating in remote were “moving from a mode of research practice in which risk was minimized to an indeterminate mode of practice, in which conditions were poorly differentiated and risk was amplified” (p. 283). In other words, Mort *et al.* (2003) verified that in our post-modern era, when ICTs are adopted in the form of telemedicine for the further

improvement of patients' welfare and the services they buy, what is actually experienced by healthcare professionals is an increased risk of misdiagnosis perceived rather than its minimization.

A number of scholars have expressed the view that *trust*, as an asset of social capital, could not be left untouched in a *risk society*, since risk is the core of trust. According to Giddens (1991), '*trust is a form of faith*' (Giddens, 1990:27) absolutely identified with the institutions of modernity, which allow *disembedding* mechanisms to be functional in the absence of face-to-face interaction. Giddens distinguishes *disembedding* mechanisms into two categories: *symbolic tokens* (such as money) and *expert systems*. Given that the current thesis studies trust development between healthcare experts⁴ and their patients via ICT, no emphasis will be given to the *disembedding* mechanism of symbolic tokens, but rather to the expert systems.

Expert systems are defined as:

“technical accomplishments or professional expertise that organise large areas of the material and social environments in which we live today” (Giddens, 1990:27)

When individuals trust professionals, such as doctors, mental-health experts, nurses or formal carers, by default, they rely on expert systems. They do not show faith in each professional or expert individually, but rather “in the authenticity of the expert knowledge which they apply” (Giddens, 1990:28). That knowledge asymmetry, or state of ignorance, creates power imbalances between a lay individual, i.e. the patient, and a professional who has that special *knowledge base*. In other words, the non-professional is “at their [professionals] mercy” (Brien, 1998:391). As already mentioned, the major contribution of *trust*, as part of the social mechanism, is that it helps reduce the complexity created by power imbalances (Luhmann, 2000). *Trust in professionals* (or *client's trust*) is defined as

“expectations of a certain kind that result in the cooperation of persons with other persons, organizational or institutions” (Di Luzio, 2004:7)

⁴ A term used interchangeably with professionals

Alternatively, we could define *trust in professionals* as a state of *faith* expecting individuals who possess expert knowledge to be scientifically and technically competent to help patients manage or resolve their health issues.

However, respectful scholars have supported that trust in professionals in post-modernity follows a downward trend. Popper (1962) holds the view, with regard to *trust in science*, that ‘all science rests upon shifting sand’ (cited in Giddens, 1990:39). Indeed, recent findings concerning trust in vaccines (Larson *et al.*, 2016) revealed that confidence in vaccine safety in Europe is found to be less positive compared to the global benchmark. Giddens emphasizes the view that “in science, nothing is certain, and nothing can be proved” (Giddens, 1990:39), while characterizing professionals and experts who possess scientific knowledge (such as doctors, lawyers, civil engineers or sociologists) as owners of a *closed shop* who use a common terminology that was invented to puzzle the layperson. That *insider’s terminology* reveals the asymmetry in knowledge and, consequently, the asymmetry in power between a layperson (often called a *client*) and a professional. Such lack of trust in an expert’s advice, together with the ongoing scrutiny and questioning of scientific knowledge, could be summarised by what Giddens calls *detraditionalization*.

“no expert system can be wholly expert in terms of the consequences of the adoption of expert principles” (Giddens, 1990:125)

Although there are subtle yet strong indications that *trust in professionals* is affected by remote communication, too little research has been done in this field. Riegelsberger *et al.* (2003) have supported that remote communication, as products of late modernity, facilitate mediated interactions that are found to be carriers of high risk. Furthermore, the authors supported that remote communication demands “more *a priori* trust than face-to-face interaction’ (Riegelsberger, 2003:760). Similarly, Andreassen *et al.* (2006), from the field of e-health, supported that remote communication affects trust. In particular, they found that fundamental elements of a patient’s trust in the doctor, such as active listening or demonstrating empathy, among others, are affected by remote communication. The authors also showed that trust in a doctor was found to be a crucial factor for a patient’s comfort in using remote communication. Although they support that remote communication has the potential of empowering a patient’s trust in a doctor, they urge that “[c]onstructing e-

mediated communication practices that promote trust and patient involvement will need careful consideration” (Andreassen et al., 2006:246). Similar to Andreassen *et al.* (2003), Nettleton and Burrows’ (2003) from the field of telemedicine and telecare have expressed concern that remote communication will alter the degree of trust in medical practice.

Lee and Zuercher’s (2017) findings indicate that remote communication between the patient and the doctor still remains under-researched. Finally, it is underlined that concerns associated with *trust issues* have been identified as one of the barriers that prevent the widespread use of remote communication between the patient and the doctor (Lee and Zuercher, 2017). However, we know too little about the role and mechanics of trust in the new digital context for the health sector.

Both the adoption of ICT by professionals for mediated interaction and communication with their patients and the identification of the risky nature of mediated interactions raise questions about remote communication putting trust in professionals at further risk. This PhD thesis anticipates contributing to knowledge by shedding light on the case of private practitioners who communicate via ICT with their patients in order to implement a medical act, either in substitution of face-to-face interaction or in supplement to traditional face-to-face sessions.

3.6 Towards the fulfilment of a research gap

It has become clear so far that the use of ICT in the patient-to-doctor relationship needs further and careful consideration. The thorough study of remote communication between the two parties should take high priority for the research community, since we are not yet aware of whether the transition from the traditional face-to-face sessions to remote ones, using any modern ICT, benefits *trust* in such relationships.

A small number of papers (Andreassen *et al.*, 2006; Nilsson *et al.*, 2010; Shea and Effken, 2008; Simpson, 2009) from the field of e-health and telecare supports that remote communication between healthcare professionals and patients could improve patient care leading to higher levels of trust. As early as 2001, the US Institute of Medicine (2001) supported that “patients should receive care whenever they need it and, in many forms, not just face-to-face visits” (p.

96), implying the adoption of ICT by the health sector. Additionally, a number of scholars from the field of sociology and telemedicine approach the implementation of ICT in the patient-doctor relationship and communication with scepticism (Giddens, 1990; Beck, 1992; Riegelsberger, 2003; Nettleton and Burrows', 2003).

It is of great importance to note that even scholars who have found that remote communication could be beneficial for the patient-healthcare expert trust-based relationship call for further and careful consideration before the adoption of such practices by the health sector (Andreassen *et al.*, 2006). As Andreassen (2011) stressed,

“there is a need for research on electronic patient-provider communication that moves beyond frequency of use and questions on how technology will affect medical encounters.” (p. 521)

Similarly to Andreassen *et al.* (2006), Lee and Zuercher (2017), as well as Santana *et al.* (2010), indicated that, in the light of electronic communication, trust between healthcare providers and patients remains unclear and needs to be addressed.

To sum up, this PhD thesis is designed to explore the role of trust in the light of remote patient-doctor communication for medical purposes from the practitioner's, rather than the patient's, perspective. As Calnan and Rowe (2006) highlighted, there is a rather small number of papers assessing trust from the practitioner's perspective compared to the sizeable volume of papers from the patient's perspective. Responding to Calna's and Rowe's (2006) call for studying trust from the expert's perspective, I have chosen to explore the role of trust in remote communication from the doctors' and mental health experts' perspective in order to contribute towards bridging this research gap.

The following chapter describes in detail my methodological choices, as well as my ontological and epistemological underpinning.

3.7 Summary

Within the framework of this chapter, it became clear that telemedicine, as a product of late modernity, tends to generate more risks than what it had been initially expected to hedge. In other words, telemedicine is a fruit of our *risk society*. Moreover, it has been presented that

the transition from paternalism to more collaborative approaches of the patient-doctor relationship, with the contribution of ICT, has turned patients from passive recipients of healthcare experts' orders to active participants in the healing and caring process. The *digitally engaged patient* has work to do (i.e., *patient work*) and work demands skills. Similarly, the *empowered patient* is expected to be an individual who owns "real management skills" (Calvillo *et al.*, 2015:644). Nowadays, when doctors and patients meet in a virtual space, where physical proximity is absent, doctors rely, to a great extent, on patients' input, and, therefore, of skills. In particular, the quality of doctors' work has become dependent, to a great extent, on the quality of the *patients' work*, *particularly* in terms of data collection (i.e., *sensory work*) and data-transfer. The distance between the patient and the healthcare expert that the practice of telemedicine assumes incorporates idle fundamental human senses, such as touch, that are still considered a cornerstone in the medical practice, as they have been for centuries. Today, it is either wearable devices or even patients themselves that have been assigned the task of medical-data collection. Such dependency on patients' skills could not have left the trust-based patient-doctor relationship untouched, given that skills constitute an integral component of trust. To sum up, the absence of physical proximity and its substitution by the interference of ICTs seem to have the power to alter some well-established and long-lasting power balances, such as that between patients and healthcare experts.

Finally, as the next chapter demonstrates, there is little knowledge about the trust-based patient-doctor relationship in the light of computer-mediated communication (CMC). Respectful researchers from the field of e-health, CMC and telework (virtual teams) have expressed concerns about the impact of ICT in the patient-doctor relationship and the very element of trust itself.

Chapter 4

CMC theories: a new perspective for telemedicine

Chapter four has been designed and structured in a such a way as to demonstrate that there is a lot for theorists and sociologists of telehealth to learn from the discipline of CMC studies. The current chapter begins by introducing key terms from CMC studies, which contribute to understanding issues regarding the risks associated with remote modes of communication, further discussed through the lens of trust. Finally, experience drawn from a variety of different disciplines (virtual teams, telework, ICT4D, telecare, etc.) regarding trust-development via ICT is discussed. Overall, chapter four demonstrates that CMC theories have the potential to provide the necessary theoretical lens and knowledge for bridging research gaps identified by theorists and sociologists of telehealth.

4.1 CMC theories: a missed opportunity for the theorists of telemedicine

As it has already been demonstrated in Chapter 3, there are subtle yet tangible indications that healthcare experts who implement medical acts in remote, concern about the emerging risk of *missed-diagnosis* or even *misdiagnosis*⁵. Such findings indicate that the shift from the traditional patient-healthcare expert physical encounter to virtual modes of encountering it is not risk-free. As Mort et al. (2003) stressed:

“[T]he shift towards virtual medical encounters creates new challenges to healthcare professionals because they have to consider whether they run the risk of missing crucial information to produce the right diagnosis when they don’t ‘see’ the patient” (Mort *et al.* 2003: 284).

In my understanding, the tele-dermatologists’ concerns in Mort et al.’s (2003) study are associated with the capacity of digital images as mediums to transfer the whole set of medical data required for an effective as well as safe decision compared to the traditional physical examination. In brief, healthcare experts raise a medium-selection issue that is none other than the: *hands-on* techniques (traditional clinical examination) vs ICT-based medical sessions in remote.

⁵ *Misdiagnosis* refers to the case of false diagnosis while *missed-diagnosis* refers to the case of inaccurate or delayed diagnosis

Although the vibrant research field of *computer-mediated communications* (CMC) has been studying for half a century medium-selection issues among geographically-distributed employees (i.e. *virtual teams*) it has been neglected -not to mention ignored- by the theorists of telemedicine. I would consider that fact as a missed opportunity because CMC scholars have produced a significant research work not only over medium-selection issues but also over trust and risk issues in virtual teams' ecosystem. Scholars studying patient-healthcare expert interactions via ICT, have a lot to learn from CMC studies and especially from the ones exploring the ecosystem of virtual teams. First, that is because virtual teams' ecosystem bears a close resemblance to the one of the patient-healthcare expert remote communication via ICT such as a telenursing service. As it has been thoroughly described in Chapter 2, in the age of *informational medicine* (Nettleton, 2004) both *remote doctors* and *absent patients* (Mort et al., 2003) are found to be spatially distantiated similar to members of virtual teams. The second common point is that the ecosystem of virtual teams and the one of telemedicine is the ICT-based communication and collaboration. Contemporary ICT provide both asynchronous and synchronous (real-time) means of communication towards the achievement of a shared goal that is none other than patient's welfare. Finally, virtual teams may be comprised by members who have either met or not in advance of the beginning of their collaboration that is also the case in the patient-healthcare ICT-based communication. To sum up, the theorists of telemedicine and e-health systems have a lot to learn from the ways that virtual team members interact and communicate among them.

One of the contributions of the current PhD thesis is that it introduces for the first time the CMC lens and jargon to the emerging field of the sociology of telemedicine in order to shed light to the role of trust in the patient-healthcare expert remote interaction via ICT. Such a merge it is expected to produce synergies between the two overlapping fields of e-health and CMC in terms of resources such as man-hours, time and research funds. Such synergies are expected to accelerate the acquaintance of new knowledge on behalf of the social scientists and sociologists who study the transformations that are taking place in the age of informational medicine between patients and healthcare experts.

Within the first half of the current section it is provided theories and findings from the field of CMC and virtual teams' ecosystem with regard to (a) media-selection (b) risk and (c) trust

issues from both positivists' (Short et al., 1976; Daft and Langel, 1983) and interpretivists' perspectives (Trevino et al., 2000; Majchrzak and Markus, 2012; Lee et al., 2007; Lee et al., 2014; Lee, 2010; Lee and Watson-Manheim, 2014; Belanger and Watson-Manheim, 2006; A. S. Lee, 1994). To sum up, the current chapter has been designed to serve as an intersection where CMC literature meets research questions and reflections from the sociology of telemedicine and e-health feeding the latter with relevant knowledge and experience.

4.2 Introducing the CMC jargon

Before moving to the core of the current chapter, it would be necessary to introduce and define key technical terms that constitute property of the CMC jargon such as the ones of *technology affordances*, *media richness* and *information richness*. *Equivocality*, *uncertainty* and *communication failure* will be defined as key terms too. Defining the abovementioned terms with precision it will help to smoothly import meaningful technical elements from the field of CMC to the field of telemedicine and e-health avoiding misuse of the jargon.

The key concept of *technology affordance* met in the TACT (Majchrzak and Markus, 2012), refers to "an action potential, that is, to what an individual or organization with a particular purpose can do with a technology or information system" (Majchrzak and Markus, 2012:1). For example, the regular telephone device as a medium employed by triage nurses for communicating with patients, it is possible to "afford" transferring verbal data such as patients' experiences or even sound data such as patient's breathing rate. On the contrary, regular phone calls can't "afford" transferring visual, haptic or olfactory data (*technology constraint*). Based on the assumption that the therapeutic technique of psychoanalysis relies to a great extent on patients' verbal data (story-telling, experiences etc.), it could provide plausible explanations about the choice of the emblematic psychotherapist Carl Jung⁶ (1875-1961) to provide his therapeutic services even in remote by exchanging letters with his patients located in remote. According to the affordance-centred approach of the ICT, that was possible because the paper as a medium has the potential to "afford" transferring data in written form.

⁶ Carl Gustav Jung (1875-1961) was a Swiss psychoanalyst and psychiatrist. He is considered as the founder of the *analytical psychology*.

The concepts of *information richness* and *media richness* are interwoven with the *information richness theory* (IRT) formulated by Daft and Lengel (1983). It is important to clearly define each concept because they are often falsely used as identical. “Information richness is defined as the ability of information to change understanding within a time interval” (Daft and Lengel, 1986:560). For example, according to the IRT if a digital image of a dermatological symptom provides substantial new understanding it should be considered by doctors as a richer medium than the telephone where symptoms can only be verbally described. *Richness* is defined as “the relative ability of information to influence or change mental representations and thereby to facilitate learning (Lengel, 1983; Daft and Lengel, 1984)”. However, information richness should not be confused and used interchangeably with the one of media richness. *Media richness* is defined as “a medium’s capacity to process information” (Daft and Lengel, 1984:7). The *richness* of a media can be either lean or rich. For example, according to Daft and Lengel (1984) face-to-face encounter and so the traditional face-to-face encounter between patients and doctors, is considered as richer than any other mode of CMC. That is because healthcare experts it is possible to collect a far wider spectrum of data from the classical physical examination compared to any ICT such as olfactory or tactile data. In brief, the greater the bandwidth of a medium the greater its information-carrying capacity. As it has become clear, *technology affordance* and *medium richness* are two terms with overlapping meanings that could be used interchangeably. Within the framework of the current PhD thesis it is been chosen the use of (technology) *affordances* instead of *media richness* because the latter term directly refers to the IRT and such a choice could raise questions about the inductive orientation of the research approach followed.

Equivocality and *uncertainty* are two terms that are also considered as integral parts of the IRT jargon. Although they look identical in terms of meaning, they are different in that equivocality describes an ambiguous situation where the available set of information leads to multiple or even conflicting interpretations. In brief, *equivocality* describes a case where critical answers it is not possible to be addressed with a “yes” or “no”. *Uncertainty* arises when the additional data collected in order to reduce equivocality, do not resolve anything. As described below, in the light of CMC the states of equivocality and uncertainty are possible to lead to *communication failures*. “Communication failure occurs when there is a mismatch between the expectation of the sender and the actions of the receiver” (Lee et al., 2007:3). For example,

in the case of tele-nursing service, any conflicting data that have been verbally transferred by the patient to the tele-nurse, it could lead to a state of equivocality and later on to one of uncertainty either due to the lack of technical expertise or due to the lack of speaking skills on behalf of the patient. Equivocality could lead to communication failure in the form of misdiagnosis. In other words, misdiagnosis might be due to the mismatch between the expectation of the health expert to receive accurate data and the failed attempt of the patient to do so.

4.3 The medium selection issue

The factors that determine the medium-selection decision have been studied since the birth of the very first CMC theories. Dominant theories such as the *social presence* (Short et al., 1976) or the *information richness theory* (Daft and Langel, 1983) have been among the first ones that attempted to map users' medium selection criteria. Although they have accepted criticism especially from interpretivists, both of the theories are still considered as influential in the wider field of CMC studies (virtual teams, telework etc.). Sections 4.3.1 and 4.3.2 demonstrate the most influential CMC theories approaches and findings that are expected to shed light to the *hands-on* techniques (traditional clinical examination) vs ICT-based medical sessions challenge.

4.3.1 The medium-selection choice: the *positivists'* perspectives and the *interpretivists'* criticism

The *social presence theory* was formulated by Short et al. (1976) and set the foundations for future scholars who studied the effect of old-school ICT such as audio-conference devices and closed-circuit television systems in societal and interpersonal interactions. *Social presence* as a term refers to "a communicator's sense of awareness of the presence of an interaction partner" (Tanis, 2003:5) that is however not separated from technology affordances of the medium. As Short et al. (1976) themselves emphasised:

"We regard Social Presence as being a quality of the communications medium. Although we would expect it to affect the way individuals perceive their discussions, and their relationships to the persons with whom they are communicating, it is important to emphasize that we are defining Social Presence as a quality of the medium itself. We hypothesize that communications media vary in their degree of Social Presence, and that these variations are important in determining the

way individuals interact.” (Short et al., 1976 as cited in Walther, 1992:55)

According to Short et al. (1976) *non-verbal signals, proximity, orientation* as well as *physical appearance* are perceived as vital elements of interpersonal communication since they contribute to the way we know and think about other people. Based on that assumption, the greater the presence, the richer the person perception. From an affordances’ perspective, that means that “the fewer channels or codes available within a medium, the less attention that is paid by the user to the presence of other social participants” (Walther, 1992:54) and vice versa. Consequently, both the sense of awareness and the social affordances of a medium it is possible to determine the medium choice. In other words, the more personal the communication the richer the medium that will be chosen. The social presence theory is still considered as a cornerstone in the CMC literature because it contributed to the birth of equally influential theories such as the *social information processing* theory (SIP) developed by Walther (1992) and the *information richness theory* (IRT) developed by Daft and Langel (1983).

Walther et al. made a significant contribution to the field of CMC in social context interaction with the *social information processing theory* (SIP) that states that social presence is not eliminated due to the reduced capacity of a medium. In particular, Walther (1992) underlined that

“given sufficient time and message exchanges for interpersonal impression formation and relational development to accrue and all other things being equal, relational valences in later periods of CMC and face-to-face communication will be the same” (Walther, 1992:69)

According to Tanis’ (2003) interpretation

“users of CMC will adapt their linguistic and textual behaviours in such a way that the presentation of socially revealing, relational signals that may normally be conveyed through a variety of channels will now be communicated via text only.” (p. 9)

Walther (1992) also supported that though CMC should not be considered as equally efficient to face-to-face communication, over time, computer mediation is expected to have little impact on relational communication.

The key characteristic of the *information richness theory* (IRT) is that it approached the medium-selection issue from the affordance's perspective similar to the social presence theory highlighting at the same time the *equivocality* factor. *Equivocality* constitutes one of the fundamental aspects of that theory. According to the IRT, the more equivocal the message, the richer the medium should be employed in terms of information-carrying capacity. Respectively, the less equivocal the message, the less rich the medium employed in terms of information-carrying capacity. Daft and Langel (1983) identified the face-to-face communication as the richest medium because all communicators have access to other persons' body language, facial expressions and non-verbal cues. Moreover, according to the IRT, face-to-face communication offers the opportunity for immediate feedback especially in the light of equivocal messages where clarifications are sought. Overall, the media-selection decision is influenced not only by the affordances of the ICT but moreover by the equivocality of the task too.

At this point it is observed that the IRT could provide adequate explanations with regard to the tele-dermatologists' (Mort et al., 2003) concerns about the capacity of the digital images to provide adequate understanding of the dermatological symptom. In accordance to the IRT and in the light of the fear of data misinterpretation, the tele-dermatologist in charge will seek for a richer media to get additional information. That richer media it is expected to provide additional understanding of the health issue to be resolved while reducing to the levels of equivocality. In accordance to the IRT, the traditional physical face-to-face patient-doctor encounter it is expected to be the optimal option in terms of both information and media richness. In other words, it would not be ungrounded to expect that both equivocality and affordances determine the media choices of the healthcare experts who operate in remote.

The IRT influenced scholars such as Whittaker (2003) who formed the *bandwidth hypothesis* according to which

“the closer the modes supported by a technology correspond to those of face to face communication, the more efficient the communication with that technology [...] adding visual information to speech should improve the efficiency of communication” (Whittaker, 2003:9)

In accordance to the *bandwidth hypothesis* which has its roots in Craig's (1975) conference paper, CMC that do not support multiple senses should lead, by default, to poorer and less efficient communication independently of task, given that neither old school nor contemporary ICT are still able to transfer data associated with the senses of touch or taste. As it has already been described in every detail in paragraph 3.4, human senses as a medium for collecting medical-data have been considered as a cornerstone in the medical science over time. However, the interference of the ICT between the human body and the healthcare expert operating in remote has been found to pose extra challenges to the medical professional. In accordance to the bandwidth hypothesis, in the light of the patient-healthcare expert CMC the detouring of smelling or touching the patient as part of the traditional medical examination process, it is expected to lead to poor outcomes. To sum up, the bandwidth hypothesis similar to the IRT supports that the information-carrying capacity of a medium to afford data that tend to simulate face-to-face encounter, determines the media-selection decision of the user.

Given that the current PhD thesis has drawn on the epistemological principles of interpretivism rather than positivism's, it would worth to be made a critical comment over the positivistic approach of the theories above mentioned and the IRT in particular. As it has been clearly demonstrated, affordance-oriented CMC theories have been formulated upon the assumption that medium's richness "remains constant, regardless of any and all differences in the individuals who use it and the organizational contexts where it is used" (Lee, 1994:145). However, ignoring the dynamic user-to-technology interaction, it might deprive researchers from coming up with unexpected findings that would take theories and thus knowledge to the next level. For example, Lee (1994) studied how richness occurred in communication via email and found that

"richness or leanness is not an inherent property of the electronic-mail medium, but an emerging property of the interaction of the electronic-mail medium with its organizational context, where the interaction is described in terms of distancing, automatization, social construction, appropriation and enactment" (p. 143)

Furthermore, the IRT has attracted constructivists' criticism because it has failed to encompass both, users' skills and the potential of employing ICT in innovative ways i.e. any use of ICT beyond designers' intentions. It was Lee (1994) again among other scholars who highlighted the aspect of innovative use. In particular, Lee (1994) supported that

“[...] the best medium or an appropriate medium for a particular communication transaction would also depend on, if not the manager’s familiarity and **existing skills** with the different media, then the manager’s willingness, opportunities, resources and support for learning the capabilities of the medium, exploring the possibilities that it opens up, **innovating uses** for it and otherwise interacting with it.” (p. 155)

It is reminded that the core of the current study is to explore the role of trust in CMC between healthcare experts and patients via products and services (mobile phones, texting services, videoconference applications etc.) that have not been designed for becoming integral parts of a telemedicine platform or application. Consequently, based on the constructivists’ rationale, using IRT as an analytical tool (i.e. deductive analysis) it would prevent researchers from shedding light to unexplored aspects of the media-selection decision such as users’ innovating skills. In other words, the IRT has failed not only in that it assumes that ICT are “fixed and immutable” (Majchrzak and Markus, 2012:3), but also in that all users realize the ICT ‘s potential the same way detouring individuals’ capacity to innovate.

Finally, all the affordance-oriented theories abovementioned have privileged the face-to-face interaction and communication over any type of CMC. As Majchrzak and Markus (2012) have mentioned “face-to-face communication is considered to be the baseline against which all mediated communication seems impoverished or diminished in some way” (p. 3). Similar findings are also coming from the field of health sociology and e-health sociology. As it has been thoroughly demonstrated in paragraph 3.3, the traditional clinical examination that includes the active involvement of all human senses, it is still considered a cornerstone in the medical practice. Moreover, it should not be forgotten the concerns expressed by the tele-nursing staff (Roing et al., 2013) or the dermatologists (Mort et al., 2003) operating in remote about the accuracy of their decisions due to the absence of proximity with the patient. However, Majchrzak and Markus (2012) have criticised that privileging of face-to-face encounter in that it “ignores the possibility that humans using technology can often enact new practices or achieve outcomes that could not occur without the use of technology” (p. 3). Such criticism gave rise not only to new theories such as the *technology affordances and constraints theory* (TACT) but also to a stream of papers from the epistemological stance of anti-positivism

that challenged the well-established ones mentioned above.

4.3.2 The medium-selection choice: the *interpretivists'* perspective

Majchrzak and Markus (2012) in response to the limitations of the IRT and positivists' perspective in general, developed the *technology affordances and constraints theory* (TACT). The TACT instead of approaching ICT as being static it recognises the user-to-technologies dynamic interactions. *Technology affordances* and *technology constraints* as relational concepts constitute the two integral components of the TACT. According to Majchrzak and Markus (2012) these two terms it is possible to overcome obstacles faced by previous theories and encompass individual's tendency to use ICT beyond designers' expectations or intentions. In brief, the comparative advantage of the TACT over previous theories is that it offers to scholars the opportunity to move beyond technology features or human purposes factor and continue by examining the interaction factor between people and technologies. Such factors might be user's ICT skills or user's tendency to innovate. To sum up, the TACT is different from the similar CMC theories in that it is "explicitly focusing attention on the non-deterministic interactions between people or organizations and the technologies they use" (Majchrzak and Markus, 2012:3).

It was also Watson-Manheim and Belanger (2007) who went beyond affordances and found that there is a variety of factors that are able to influence the composition of *communication portfolios*⁷ and thus the media-selection decision. Watson-Manheim and Belanger (2007) found that the use of communication portfolios is influenced by a variety of *institutional*, *structural* and *routine* factors. Trust that is the core of the current thesis, it was found to be one of the most influential institutional factors among others such as the physical proximity and the organizational incentives. In particular, they found that interpersonal trust levels influenced both behaviour and usage patterns of the ICT. The structural factors influencing the

⁷ *Communication portfolios*, also known as *media repertoires*, refer to a group of ICTs that consists of a single or multiple ICTs that it is possible to vary in terms of *size* (the total number of ICT utilised), *content* (the mixture of ICT) or *structure* (Lee et al, 2007). The structure of a communication portfolio also known as *structuring mechanisms*, refers to "the usage pattern of a single or combination of ICTs to manage risk perceptions during communication" (p. 6). Lee et al. (2007) identified three types of structuring mechanisms that are the *sequential* (i.e. switching from one ICT to another), *concurrent* (i.e. using two or more ICT in parallel) and *repetitive* (i.e. using the same ICTs more than once).

media-choice decision were the messages' urgency or the task characteristics among other factors such as the message's characteristics. The routine use of the ICT over time was also found to influence the media-selection decision and thus the composition of the communication portfolio. Overall, Watson-Manheim and Belanger (2007) questioned and challenged the strict richness-based approach of the media-selection decision. In particular they concluded that "looking at the richness of the media or the equivocality of the tasks is not enough" (Watson-Manheim and Belanger, 2007:287).

The role of trust as a determinant in user's medium-selection choice has also been highlighted by Lo and Lie (2008). According to Lo and Lie (2008)

"as the level of trust between communicating parties increases, media with a lesser degree of information richness is often selected in long-distance communication situations" (p. 151)

Respectively

"if significant distrust exists between the partners, the tolerance level of perceived risk during the interaction will be lower, and the communicator will likely opt for a communication channel with a higher degree of information richness that transmits more information, in order to lower the degree of uncertainty inherent in the interaction." (p. 148)

They also underlined that the above-mentioned patterns apply in long-distance communication situations. At this point it is worth highlighting that Lo and Lie's work is the first that unravelled and revealed to such an extent the key role of the communicator's trustworthiness in remote communication.

However, it was not only interpretivists who questioned the inflexible affordance or richness-oriented approach of the medium-selection decision. It has been the founders of the IRT themselves who revisited and reviewed the media-selection choice from the interpretivists' perspective in a paper that they co-authored with Trevino (Trevino et al., 1987). Trevino et al. (1987) followed the *symbolic interactionist* perspective far from the positivistic approach of the IRT to observe that there were managers (in the role of ICT users) who selected media even randomly. In brief, Trevino, Lengel and Daft (1987) challenged the strength of the equivocality

and affordances as the only factors affecting the media-selection decision. In particular, they found that *situational determinants* such as *distance*, *expediency*, *structure*, *time pressure*, *accessibility of the medium* and *critical mass of users* are possible to affect users' media-selection choice. Moreover, they found that mediums themselves as carriers of meanings, can have a significant effect on media-selection behaviour. To sum up, Trevino et al. (1987) confirmed through the lens of interpretivism and symbolic interactionism in particular (a) the power of the *message equivocality* as a factor capable of influencing the media-selection criteria and (b) the influence of the medium's *symbolic meaning* itself along with a group of situational factors.

The concept of *perceived risk*, it has been identified as a factor that influences medium-selection decision. Lee and Watson-Manheim (2014) explored the role of perceived risks in CMC between two globally distributed software development teams and they identified "significant differences on the effects of perceived risks in communication on the use of frequently used ICT" (p. 23). Although they found that the effects of perceived risks on ICT use were not common for the two teams, it would be safe to extract the conclusion that risk perceptions seem to influence the media-selection decision. Risk perceptions have also been found to determine the structuring of single and multiple ICTs (i.e. *communication portfolio* or *media repertoire*) and thus the media-selection decision. In particular, Lee et al. (2014) found that virtual team members in the light of high perceived risks in the message and information component, they used to seek for additional information (i.e. *information gaining behaviour*). That goal was achieved by making either combinatorial use of ICT in *sequence* i.e. *sequential structuring mechanism* or through the combinatorial use of ICT in *parallel* i.e. *concurrent structuring mechanism*. The *concurrent structuring mechanism* refers to the combinatorial use of ICT in parallel such as texting while participating in a voice conference. The *sequential structuring mechanism* refers to the use of ICT in sequence or the use of one ICT followed by another successively. Lee et al. (2014) also found that communication channels considered as poor in terms of richness such as email, it used to perform effectively in the light of high perceived risks in the action component. In particular, they found that email as well as instant messaging services used to perform effectively in cases where the receiver required to be pressured in order to take some actions. Finally, they found that in the light of low perceived

risks virtual team members used fewer ICTs as well as that face-to-face communication was preferred in the light of non-task related interactions (i.e. social).

However, it would be worth to identify the key differences between *risk perceptions* and *risk*. As it has already been mentioned, well-recognised CMC theories have received significant yet justifiable criticism from scholars who epistemologically belong to the school of anti-positivism. There are scholars from the field of CMC such as C. S. Lee, M. B. Watson-Manheim and K. M. Chudoba, who have founded their research work over the assumption that risk is socially constructed in sharp contrast to positivists' assumption that risk is an objective state of nature. In other words, what constitutes a risk for user X does not constitute a risk for user Y. Nevertheless, there are findings supporting that individuals do not make risk assessments based on probability formulas but instead based on their "feelings towards the risk" (Lee and Watson-Manheim, 2014). In response to that ontological divergence, the concept of *perceived risk* has been preferred instead of the one of *risk*. However, perceived risk should not be confused with the one of *uncertainty*. *Uncertainty* refers to "threats that are capable of producing adverse consequences" (Lee et al, 2007:2). Perceived risk "measures beliefs of the uncertainty regarding possible negative consequences" (Lee et al., 2007:2) while *perceived risks in communication* "refers to the perceived problems that may influence one's ability to accomplish communication goals" (Lee et al., 2014:690).

Finally, it was Lee (2010) who challenged the omnipresence of the IRT and the *bandwidth hypothesis* too. As it has already been described, according to the IRT the element of equivocality it is possible to be managed using medium's richness (technology affordances). In particular, the more equivocal the message the richer the medium should be used in order to eliminate the oncoming communication risks. In other words, the IRT as well as the bandwidth hypothesis acclaim the face-to-face communication as the richest medium possible to minimise any communication risk. Although Lee (2010) recognised the influential power of affordances in the medium-selection decision, he challenged the core of both the IRT and the bandwidth hypothesis. In particular, he found that "communication with low perceived communication failures tend to favour the affordances provided by FTF communication while high perceived communication failures tend to prefer the affordances provided by the combination of email and telephone/teleconferencing" (Lee, 2010:577). In sharp contrast to

the IRT, Lee (2010) found that the affordances of low mediums in terms of richness such as the ones of email and telephone/ teleconferencing, they were helpful to manage high perceived communication risks. Respectively, the affordances provided by the richest medium i.e. face-to-face communication, “were often used during communication with low perceived communication failures” (Lee, 2010:578). Lee’s (2010) findings have been in line with Nardi’s and Whittaker’s (2002) findings who found that face-to-face communication should not be considered by default as the most effective medium of communication in every single working environment. As Lee (2010) explained

“face-to-face communication does not afford persistence communication which is especially critical in software development work setting because problems and issues usually need to be documented, reviewed and referenced by team members or team leaders later” (p. 579).

Lee (2010) unravelled the potential of the interpretivists’ perspective by suggesting that the medium-selection decision and CMC in the working environment should not be studied cut off from the nature of the work and its communicational needs.

To sum up, from an interpretivist’s point of view, equivocality and medium richness are not capable of explaining and unfolding the media-selection choice on their own (Lee and Watson-Manheim, 2014). It is common sense that the affordance, equivocality and richness-oriented approach of the medium-selection choice are capable of unravelling part of the users’ media-selection decision yet there is a wider group of factors that influence such a decision. The interpretivists CMC theorists demonstrated that the user-to-ICT interplay is dynamic and extends beyond the technology features. As Grint and Woolgard (1997) argued “the relevance of technology lies in actor interpretive activities rather than in any objective account of its capacities or effects” (Grint and Woolgard, 1997:138 as cited in Watson-Manheim and Belanger, 2007:287).

What follows is an emphasis over the role of *risk (perceived communication risks)* and *trust* in the setting of the CMC because both elements are located at the core of the research interest of the current PhD thesis.

4.4 Communication risks in CMC: lessons learned from virtual teams

As it has already been clarified, the transition from the traditional patient-healthcare expert physical encounter to virtual ones has not come risk-free. As Mort et al. (2003) stressed:

“[T]he shift towards virtual medical encounters creates new challenges to healthcare professionals because they have to consider whether they run the risk of missing crucial information to produce the right diagnosis when they don’t ‘see’ the patient” (Mort *et al.* 2003: 284).

From a CMC perspective, what Mort et al. (2003) highlighted was that the risk of misdiagnosis as a form of *communication failure* (Lee et al., 2007), emerged from the limited affordances of visual images as mediums. In particular, Mort et al. (2003) expressed tele-dermatologists’ worries due to the incapacity of the digital image as a medium to afford transferring a group of important medical data (haptic, olfactory etc.). Moreover, when Mort et al. (2003) were referring to the risk of “missing crucial information” (p. 284) due to the lack of physical or eye contact with the patient, they were actually identifying a gap that exists between the data should be collected and assessed and the data that it was finally possible to be collected and assessed in remote. According to Mort et al. (2003), the data-gap identified gives rise to the risk of misdiagnosis. However, it was not Mort et al. (2003) who mentioned for the first time that remote modes of interaction via ICT inhibit risks.

Lee et al. (2007) from the field of CMC and virtual teams’ studies, highlighted that “any communications involving the use of ICT are very prone to a certain degree of risk and threats to poor communication” (p.3). In particular, Lee et al. (2007) implemented a large-scale literature review paper where they managed to group to three broad categories a number of perceived communications risks associated with CMC. The three overarching communication risk categories were the (a) *risk of reception*, (b) the *risk of understanding* and finally (c) the *risk of action*. It is important to highlight that Lee et al.’s (2007) literature review paper has focused to a great extent to CMC risks arising from human-to-human interaction which is also the case in my PhD i.e. the patient-healthcare expert CMC.

The *risk of reception* regards all the risks associated with the generation, transmission and reception of the message. In particular, the risk of generation regards any communication failure originated from the lack of familiarity with ICT or ICT skills of the sender. Similarly,

transmission challenges are also associated with the user's familiarity with the ICT as well as with technical issues concerning the medium itself i.e. hardware, software issues etc. It should not be forgotten that affordances are potentials for actions that may not necessarily occur (Markus and Silver, 2008). That said, it is also up to user's skills (ICT literacy) to make the most out of the potential offered by the medium.

The *risk of understanding* is mostly cognitive-oriented since it is affected by the receiver's correct understanding and interpretation of the information transferred by the sender. For example, in the setting of the patient-healthcare expert remote communication it could be expected that patients with cognitive decline due to ageing, it could give rise to the risk of understanding. Moreover, the perceived risk of understanding it is also prone to affective components often included in communication. According to Lee et al. (2007), past research has revealed that affective components employed in remote communication contribute to the understanding of a message. It has been found that medium's technology affordances have the opportunity to support or even block the transmission of affective data such as facial expressions, voice tone, voice texture, gestures etc (Lee et al., 2007). In particular, when a medium's bandwidth cannot support the transfer of affective data, it is making it more difficult for the receiver to fully understand the content of the message giving rise to the risk of misinterpretation and finally to the risk of misunderstanding. I would consider that finding as a valuable one for the research interests of the current thesis given that the patient-doctor trust-based relationship lies to a great extent to a group of affective components like human touch in the form of hugs that cannot be afforded by any ICT at the moment. Moreover, ICT can also affect the risk of understanding especially in the case where both communicators lack of shared understanding i.e. share different backgrounds (Lee et al., 2007). That should be considered as a valuable finding for the theorists of telemedicine because this is actually the case in the patient-doctor remote communication via ICT. In particular, we have a case of remote communication via ICT where significant asymmetries in terms of technical expertise and scientific knowledge exist between the patient and the doctor by default. Consequently, it would not be ungrounded to expect that the lack of expertise on behalf of the patients could give rise to the risk of understanding undermining the quality of the communication and finally the decisions made by the doctors. For example, how possible would it be for a patient to describe in an accurate manner by phone a number of body symptoms without missing any

crucial information given the lack of his/ her expertise and the cognitive decline he/ she is suffering from due to ageing. To sum up, factors such as *cognition*, *affect* and *shared understanding*, have the potential to give rise to the risk of understanding undermining the quality of the communication and thus the quality of the decisions made.

The third group of communication risks identified by Lee et al. (2007) associated with remote communication via ICT is the *risk of action*. The risk of action is concerned with whether the receiver of the data actually implemented the required action. For example, in the case of the patient-healthcare expert remote communication the concern might be whether the non-professional carer of the patient or the patient him/ herself implemented with accuracy a medical action regardless of its complexity levels. The risk of action encompasses three individual risks: (a) the risk of *inaction*, (b) the risk of *incorrect action*, and finally the risk of (c) *in-adaptive action*. The *risk of inaction* refers to the case where the receiver of the message ignored the sender's instructions. Such a case in the setting of the patient-doctor remote communication might result to fatal outcomes. For example, what would be the consequences in the case of a non-disciplined parent who ignores the instructions of a telephone nurse for immediate vaccination of the child? The *risk of incorrect action* is concerned with whether the receiver of the instruction-based messages executed the tasks the proper way. As it is been demonstrated in Chapter 6, doctors interviewed expressed concerns about the risk of incorrect action that it is possible to affect their trust-based relationship with their patients. In particular, it was found that patients or non-professional carers (see parents) who do not have the necessary skills to effectively accomplish simple medical tasks under no surveillance, might be considered as untrustworthy. Finally, the *risk of in-adaptive action* refers to the case where the receiver lacks critical thinking and thus "blindly" takes the "right" action without a good understanding of the instruction-based message. In other words, the receiver "may not be able to adapt the action if the situation or the condition changes" (Lee et al., 2007:6).

To sum up, there are findings from the field of CMC that the risk of communication failure is amplified when individuals are not co-located but instead, they are distributed co-workers (Armstrong and Cole, 2002). Such findings are proof of evidence that the theorists of telemedicine have a lot to learn from the field of CMC and virtual teams' literature. It should not be forgotten that in the age of the *empowered patient* and *informational medicine*

(Nettleton, 2004) patients and healthcare experts communicate and collaborate remotely via ICT similar to virtual team-members.

4.5 A trust-oriented approach of the *communication failures*: a personal note

As it has been emphatically mentioned in Chapter 2 there is no trust issue in the absence of risk. Based on that assumption, the presence of risk will always be signalling trust issues. Consequently, the emerging risk of misdiagnosis as a form of communication failure in the light of the patient-healthcare expert CMC, it should be expected to raise trust issues too.

For example, approaching Lee et al.'s (2007) paper from a trust perspective that is the core concept of the current thesis, it becomes clear that the lack of skills i.e. one of the fundamental ingredients of trustworthiness, dominates as a risk factor in CMC. The risk of generation and thus the risk of reception have been associated with the user's ICT skills or familiarity with the ICT. Similarly, limited cognitive skills are possible to foster the risk of understanding or even the risk of action due to the making of false decisions (see the risk of incorrect or in-adaptive action). Respectively, analytical skills such as critical thinking are possible to give rise to the risk of incorrect action or in-adaptive action. As Lee et al. (2014) have highlighted, perceived risks in communication refer to "the perceived problems that may influence one's ability to accomplish communication goals" (p. 690). To sum up, skills have been found to raise communication-risk issues.

Another case where the absence of the necessary skills could raise risk and thus trust issues is the one of the telephone triage nurse service (Roing et al., 2013). From a communication risks' perspective, the lack of the required communication skills (i.e. speaking skills) on behalf of patients who are not native speakers, could be responsible for feeding the tele-nursing staff with incomplete or even inaccurate data. That lack of basic communication skills on behalf of the patient could lead the tele-nursing staff into *incorrect actions* (Lee et al., 2007) and finally to a number of *communication failures* (i.e. misdiagnosis). That is because tele-nurses rely exclusively on patient's descriptions for making their decisions because landlines as a medium cannot afford transferring any other data except from verbal. Consequently, any suspicion on behalf of the nursing staff regarding the accuracy of the data transferred by the patient, could

downgrade patient's trustworthiness in terms of skills that is one of the fundamental ingredients of trust.

Similarly, healthcare experts working over the cardiac telemonitoring system (Oudshoorn, 2008) rely not only on data recorded by the patient to the ECG device but also on data collected verbally by the patients in the aftermath of health events. Any interpretation or decision is based on both pools of verbal (*anamnesis*) and non-verbal data. It is apparent that in the absence of physical proximity, healthcare staff becomes dependent to *patients work* (Lupton and Maslen, 2017) and thus to the quality of each patient's skills-set.

To sum up, research from the field of CMC and virtual teams suggest that "[T]he ability to effectively use single as well as multiple ICTs to accomplish communication goals during the communication process is a critical skill in organizations today" (Lee et al., 2014:689). Consequently, it would not be ungrounded to expect that patients' skills (ICT, communicational, cognitive, aptitude etc.) will alter the trust balance between the healthcare experts and the patients (non-experts). Traditionally, the patient-doctor relationship has been a one-way trust-based relationship where only doctor's trustworthiness mattered. In the age of *informational medicine*, when the traditional face-to-face encounter has been supplemented or even totally substituted by CMC, healthcare experts seem to rely more on patients' skills and expertise (see the *sensory work* by Lupton and Maslen, 2017) for collecting data that is either not possible to be collected by themselves or afforded by the medium employed.

4.6 Trust development via CMC

4.6.1 The case of virtual/ teleworking teams

The major body of literature in the field of teleworking and CMC has mostly studied trust development among teleworking teams (virtual teams, collaborative teams etc.) where each team member (teleworkers) decides to bear the risk of trusting others or where each team bears the risk to trust other teams in a framework of achieving a common goal.

Bos et al. (2002) studied trust development within virtual teams working remotely in a social dilemma game in four different situations: face-to-face, video, audio and text. They found that

CMC have an effect on trust development but also that communication via video, audio or text, were found to have some drawbacks compared to face-to-face communication, though video and audio channels performed nearly as good as face-to-face communication in overall cooperation. Bos et al. (2002) also found evidence that there are two different modes of trust: *delayed trust* and *fragile trust*. *Delayed trust* refers to the phenomenon whereby it takes longer for an individual to trust a new partner and communicate his/her own trustworthiness in the absence of body language signals, facial expressions and voice fluctuations. *Fragile trust* refers to the phenomenon whereby teams that cooperate through mediated communication are “more vulnerable to opportunistic defections and subsequent fallout from defections” (Bos et al., 2002:139), even when cooperation has already been established.

Wilson et al. (2006) examined how cooperation and trust develop among team members who work either virtually or face to face with no prior familiarity. They found that “that trust started lower in computer-mediated teams but increased to levels comparable to those in face-to-face teams over time” (Wilson et al., 2006:16). The same phenomenon was also observed in teams that shifted from face-to-face communication to CMC and vice versa. Finally, they found that high levels of inflammatory comments were associated with decelerated development of trust in CMC teams.

Similarly, Zheng et al. (2002) found that participants who have previously met at a number of social activities before using CMC, establish higher levels of trust compared to those who have never had even a preliminary meeting either in the form of face-to-face contact or via text-chatting. Moreover, Rocco (1998) revealed the Rocco (1998) found that strangers who had no prior meetings before starting to collaborate on a team-building exercise, underperformed compared to those who had prior communication, even via email.

Riegelsberger et al. (2003) underlined the significant effect of CMC on trust development as a risk catalyst. In particular, they emphasized *risk* as a core element of computer-mediated interactions with regard to people who are called to collaborate and are placed in different contexts or cultures. Moreover, the possibility of misinterpretation is increasing while the imposition of rules and agreements appears to become more difficult. They also considered *a priori* trust as more necessary for implementing any form of computer mediated communication or interaction than in a face-to-face context. Riegelsberger et al. (2003) also

emphasized the inadequacy of CMC to embrace all the richness of face-to-face interactions, essentially due to omitted cues, which are considered crucial to developing trust-based relationships.

Finally, levels of trust towards the communication partner were found to play a critical role in user's medium selection (Lo and Lie, 2008). According to Lo and Lie (2008)

“as the level of trust between communicating parties increases, media with a lesser degree of information richness is often selected in long-distance communication situations” (p. 151)

Respectively

“if significant distrust exists between the partners, the tolerance level of perceived risk during the interaction will be lower, and the communicator will likely opt for a communication channel with a higher degree of information richness that transmits more information, in order to lower the degree of uncertainty inherent in the interaction.” (p. 148)

They also underlined that the above-mentioned patterns apply in long-distance communication situations. *Task equivocality* and *trust* have no influence on users' choice of media. At this point it is worth highlighting that Lo and Lie's work is the first that unravelled and revealed the key role of the communicator's trustworthiness in remote communication. Finally, Watson-Manheim and Belanger (2007) found that *interpersonal trust* among the members of virtual teams, it is necessary for the seamless and effective communication among them. They also found that the absence of trust results to ICT usage patterns that are possible to hinder not only the quality of communication but also the effective management of resources and employees' job-satisfaction levels. In particular they stated that

“using communication media in a dysfunctional manner, such as when usage patterns reflect low levels of interpersonal trust, can lead to decreased effectiveness in communication, wasted effort and frustration for employees and wasted resources in the organization.”

To sum up, CMC scholars have highlighted the value of trust in the light of CMC that should be approached and valued as an intangible asset. Though there are still contradicting findings about the effectiveness of teams that have already established bonds of trust compared to

those who had not even met before, there is no doubt that it is important for virtual team members to know each other in advance of the project. The value of pre-existing bonds of trust have not been stressed only from CMC scholars but also from theorists of e-health and telemedicine. As it is being demonstrated in the following paragraph, Andreassen et al. (2006) found that pre-existing bonds of trust between doctors and patients who communicate in remote favours CMC use on behalf of the patient.

4.6.2 Experience of CMC from ICT4D studies

ICT4D scholars have also studied the impact of computer-mediated communication on trust development. Through the perspective of trust, Molony (2007) studied how ICT is being employed by Tanzanian micro and small enterprises. He also suggested that

“the need for direct, personal interaction through face-to-face contact -a traditional pre-ICT aspect of African business culture- is unlikely to change for some time” (Molony, 2007:67)

Molony (2007) reconfirmed Handy’s (1995) results that ‘trust needs touch’, given that face-to-face communication encompasses all the senses and thus constitutes the richest medium. He also found that ICT is mostly employed as a tool for business communication (either with customers or other businesses) when face-to-face contact is not feasible due to geographical constraints. A strong statement of an interviewee that *‘I don’t trust the telephone; it always lies’* (Molony, 2007:76) reveals that mobile phones can be seen as a technology which holds the power to facilitate business related communication for already established relationships. However, he suggested that the need for live interaction is not possible to change in the near future.

4.6.3 Experience from e-medicine, tele-care and e-therapy

Andreassen et al. (2006), found that ‘patients’ use of ICT and the element of trust in the patient-doctor relationship influence each other’ (Andreassen et al., 2006:238) while they associated *personal trust* with patient’s comfort in using CMC (Andreassen et. al, 2006). At this point it should be highlighted that Andreassen et al. (2006) confirmed the findings of Zheng et al. (2002) and Rocco (1998) about the importance of a pre-existing, well-established trust

relationship between the patient and the doctor. Although they recognize that CMC, like any communication channel, has substantial potential to empower the patient's trust in the doctor, they claim that a positive outcome is not always guaranteed and thus such practices demand further and careful consideration.

In their case study, Nilsson et al. (2010) described the experiences of two Swedish district nurses in the use of ICT for supporting people with a serious chronic illness living at home. Though physical presence is still considered as irreplaceable, their results revealed that nurses felt that the *increased accessibility* offered by ICT to nursing care (electronic messaging programs via computers and mobile phones with access to Internet), offers the potential for the development of a more trusting relationship. In other words, tele-home care offers patients the potential to access the district nurses at any time, which may lead to a solid trust-based relationship. Both district nurses also underlined the importance of *knowing the patient* before the implementation of the tele-care program, as necessary for creating the necessary conditions for individual care. With regard to the item of *accessibility*, similar results reported by Bültzingslöwen et al. (2005) who found that *reaching the doctor* –i.e. accessibility- often offered the patient a sense of security, especially if they knew the exact way to get in touch with him/her.

Shea and Effken (2008) from the field of nursing, suggested three strategies for overcoming barriers that inhibit trust development in remote between nurses and patients focusing on the nurse's perspective. In particular, Shea and Effken (2008) supported that *demonstrating ability, integrity* and *benevolence* which are considered as key strategies for developing and maintaining trust in traditional face-to-face interactions, are also applicable to computer mediated interactions. Though they highlighted the significant contribution of body language and physical touch (a hand on a shoulder, sight, touch, smell, voice) to trust formation between the nurse and the patient, they emphasised the *accessibility* offered by ICT as an element that offers the opportunity for trust empowerment. In more detail, they supported that the *accessibility* offered by ICT facilitates communication in any form such as short talks, advice and instruction giving, which are considered extremely valuable for the development of trust. They concluded that both synchronous and asynchronous ICT offer the potential to have a positive effect on trust and its three characteristics of *ability, integrity* and *benevolence*.

Delbanco et al., (2004) also held the view that e-mail offers both to doctors and patients extra time for thought and processing earlier defined by Suler (2000) as *reflection zone*. In particular, they mentioned that “doctors and patients move closer together, and trust grows strikingly” (Delbanco et al., 2004:1707). Similar indications offered by Yager (2001) who reported that patients suffering from anorexia nervosa stressed that emails offered to them a sense of being more in touch with and taken care by the healthcare expert.

Simpson (2009) from the field of psychotherapy supported that according to limited research, there are patients who prefer remote sessions via video-conference applications compared to regular face-to-face session because they “feel less intimidated and more in control of their sessions” (p. 274). They attributed that kind of feeling to patients’ potential to end their session at any time while being at their own premises instead of in the MHE’s territory. Simpson (2009) supported that the power imbalance in face-to-face therapy sessions is greater than in remote sessions since the sessions are implemented in the MHE’s territory. Finally, they supported that for some patients, that asymmetry offers ‘a sense of safety while for others it undermines openness and trust’ (p. 275).

Similar findings have been reported by Bjerke et al. (2008) who found that SMS messages offered patients, struggling with substance abuse and psychiatric disorders, a sense of proximity to the MHE even though the MHE was not physically present. That kind of presence defined and coded as ‘perceived presence’ (p. 199) by Bjerke et al. (2008), has been explicitly described by one of the participants as “a permanently outstretched hand from a person who cares” (p. 199). Moreover, Bjerke et al. (2008) reported that the MHE who is accessible remotely, is experienced by patients as someone who is continuously available to address questions or to actively listen to their experiences. To sum up, SMS messages offer patients a sense of being connected with their MHEs.

To sum up, it is clear that there is still a lot of research work to be done over the elements of trust and accessibility offered by ICT and the way both items serve each other.

At this point, it is of critical importance to highlight that, if the sophisticated e-health technologies demand a skillful patient or informal carer to become functional, then inequality issues regarding accessibility are about to emerge. Policy makers should be well aware of the

fact that not all patients or informal carers possess the necessary skills to turn these technologies to accessible ones and, hence, make the most out of them. As Henwood *et al.* (2002) stressed: “[W]hen it comes to the information *media*, access issues concern the possession or acquisition of the skills, and knowledge necessary to the particular media, ranging from basic literacy through computer literacy to high level web-searching skills.” (p. 88). Just like Henwood *et al.* (2002), Norman and Skinner (2006) distinguished six core skills or literacies *in regard to e-health literacy*, namely, that being health literate at the age of digital health, requires “an expanded set of skills, incorporating six core skills or literacies: traditional literacy, health literacy, information literacy, scientific literacy, media literacy and computer literacy” (Marshall *et al.*, 2012:480-481). In my view, e-health developments, as well as technologies designed by product developers and promoted by policy makers, should be as user-friendly as possible in order to prevent the emergence of digital divide issues.

Chapter 5

Methodology

The current section is designed to provide in detail, the rationale behind my methodological choices. In particular, it provides an insight into my *ontological* and *epistemological* conceptions as well as how

these affected my decision this study to *draw upon* grounded-theory techniques. Additionally, it demonstrates the rationale behind the *sampling* techniques, the coding toolkit employed for data-analysis as well the actions taken in order to produce a *valid* and *credible* research output. Furthermore, it provides personal reflections and accounts about challenges that arose during the stages of research design, data-collection and data analysis such as the one of defining trust or handling literature review. Finally, *ethical issues* are addressed in a detailed manner.

5.1 My ontological and epistemological underpinnings: from the *Platonic Cave* to Freud and *pragmatism*.

I hold the personal view that the *ontological* and *epistemological* conceptions of social researchers should be clearly answered and revealed even before choosing which methodological path to follow. It is crucial for the researcher to be aware of the way he/she places him/herself in the *social* and *natural universe*. It is also of great importance for the researcher to be aware of the way he/she perceives and defines fundamental notions such as *reality, truth, knowledge, material world* or *world of senses, objectivity etc.* This is because each concrete research methodology (grounded theory, phenomenology, ethnography, content or thematic analysis etc.) relies upon very specific ontological and epistemological assumptions. For instance, *realism* offers a far different perspective of what we perceive as *real* than *materialism*. Even scholars who appear to contribute to the development of the same research methodology often have different ontological assumptions leading to various versions of the very first research (i.e. the grounded theory case).

Once the researcher has become aware of his/her ontological perceptions, he/she should move on to the next step which deals with the way that *knowledge* and *truth* will be explored. In other words, the researcher should explore and reveal his *epistemological* conceptions, answering fundamental questions such as “*how can I know about reality?*” or “*what is the primal matter of our knowledge?*”. There are two major epistemological trends: *positivism* and *interpretivism*. According to *positivism*, the world is both independent of and unaffected by the researcher, while human societies, like the physical world, operate based on laws, rejecting both introspective and intuitive knowledge. *Interpretivism* (often called *anti-positivism*) holds that research methods of the natural sciences are not appropriate for studying the social world

given that the latter, in sharp contrast to the former, does not operate according to law-like regularities. While objectivity is rejected, it is assumed that the researcher and the social world interact. I would support that there are not “yes and no” answers to such major existential and epistemological questions and that researchers should be aware of the school of thought they belong to, or feel to be the closest to their epistemological conceptions.

Plato (429-347 B.C.E.) in his cornerstone work *The Republic*, summarizes his ontology through the following imaginative conception:

“Prisoners are seated, staring at a Cave wall onto which are projected images cast from carved figures. These figures are illuminated by a fire and carried by people on a parapet above and behind the prisoners. The prisoners are chained so that they cannot move their heads. One prisoner is freed from his chains. The first things he sees are the fire and the carved images. He is then allowed to step out of the cave and into the real world. The strong light of the Sun blinds him and he is unable to observe the trees, the rocks and the animals around him. Instead, he can only look at the shadows and reflections in water that those objects cast. As he slowly acclimatizes to his environment, he is able to look at those objects, and when he is finally fully acclimatized, he is able to recognize the Sun and the source of illumination.”

In terms of ontology and epistemology I am influenced by the *Platonic* approach to the *real world* in that the latter appears to our senses in a way filled with errors/illusions. In the analogy of the Cave, the carved statues represent the physical objects upon which belief is set. Plato’s approach to the ‘real world’ reminds me of the Freudian concept of *projection* i.e. “the defence mechanism by which a person attributes to someone other than himself a trait, affect, impulse, or attitude that is really his but that is too painful, and thus unacceptable to him” (Blumberg and Maher, 1965:311). Freud’s concept of *projection* appears to meet *idealism*’s basic principle according to which an external reality does not exist independently of our beliefs, understandings and experiences.

Though I do not perceive myself either as a pure *idealist*, a *realist* or an *objectivist*⁸, I would rather classify myself as a *relativist*, which is considered a variant of idealism. *Relativism*,

⁸ Reality exists independently of our consciousness while human beings have direct contact with reality through their senses

similarly to *idealism*, supports that reality becomes knowable “only through the human mind and socially constructed meanings” and that “there is no single shared social reality, only a series of alternative social constructions” (Ritchie and Lewis, 2003:16). Protagora ‘s (c. 485-410 B.C.) who is considered the father of *relativism*, summarised the essence of *relativism* in the following statement:

“the human being is the measure of all things, of those that are, that they are, and of those that are not, that they are not”

At this particular stage of my research, I face the fundamental *epistemological* question: “*how is it possible to know about the world?*”. Between the two major epistemological stances i.e. *positivism* and *interpretivism*, I would place myself in the latter school of thought. Both the influential writings of Plato and my personal life experiences so far, have led me to the conclusion that it is not possible for human beings to become either independent or objective observers of any phenomenon taking place in the social arena. Though human beings appear to act based on some law-like regularities they do, in fact, project upon other people primal elements of their personality which has been constructed upon past experiences. Consequently, I cannot support with certainty that it is possible for any observer such as a social researcher, to read and record social phenomenon or social interactions either independently or objectively. Rather, I think that it is more meaningful in terms of feasibility, to explore and understand the social world through my own eyes – “explore and understand the social world through the participants’ and their own perspectives; and explanations can only be offered at the level of meaning rather than cause” (Ritchie and Lewis, 2003:23).

However, I think it should be highlighted that social researchers who follow the path of *interpretivism* should be, as much as is possible, self-aware. Though absolute objectivity seems to be a non-achievable status, self-awareness helps researchers not to *project* observation traits, affects, impulses, or attitudes that really belong to themselves as much onto their sample. It is worth to recall at this point what Plato mentions in his work *Phaedrus* where Socrates says (229e)

“I am not as yet able, as the Delphic inscription has it, to know myself; so, it seems to me ridiculous (230a), when I do not yet know that, to investigate irrelevant things”

5.2 Choosing the most appropriate research methodology

5.2.1 GT as a sophisticated research vehicle: approaches adopted, and tools employed

I would consider as of crucial importance to highlight that the current study *draws upon* GT techniques, as those were described by Charmaz (2014), rather than being a pure GT study per se. What led me to this decision were the kind of questions answered by GT.

Grounded theory is the study of a concept aiming to generate or discover a theory. In particular, GT was initially designed to help social researchers to move with a systematic, flexible and at the same time sophisticated way from data to theory. The aim is the development of new theories that emerge from the data and which, according to the *classic* GT approach, have avoided at all cost, the imposition of meanings onto the data. According to its founders Glaser and Strauss, GT is defined as “the discovery of theory from data systematically obtained and analysed in social research” (Glaser and Strauss, 1967:1).

According to the representative of the *constructivist* approach, Cathy Charmaz, GT:

“Consists of systematic yet flexible guidelines for collecting and analyzing qualitative data to construct theories from the data themselves [...] Grounded theory begins with inductive data, invokes iterative strategies of going back and forth between data and analysis, uses comparative methods, and keeps you interacting and involved with your data and emerging analysis” (Charmaz, 2014:1)

The three key features that motivated me to follow GT were *firstly*, the fact that GT is considered as an ideal methodological choice where no previous theory exists, *secondly*, the fact that it has been used effectively for many years in the field of healthcare and *thirdly*, the conclusion that GT ‘makes even more sense when dealing with new phenomena, such as information technology, that have permeated most aspects of social life’ (Urquhart, 2013:17). As was mentioned in the introduction, the research question seeking an answer in my thesis is “*how do healthcare professionals and experts experience computer-mediated communication with their clients in regard to trust?*”. My research question is in accordance with the previous three conditions: *firstly*, it attempts to explore remote communication between patients and

doctors and hopefully establish a theory for a phenomenon that still remains unexplored, *secondly*, it belongs to the broader field of healthcare studies, and *thirdly*, it attempts to study the emerging phenomenon of ICT impact on fundamentals of social life, such as the relationship between the MHE/doctor and the patient. Finally, grounded theory has had a long tradition in raising and addressing analytic ‘why?’ ‘what?’ and ‘how?’ questions (Charmaz, 2014).

5.2.2 Choosing the appropriate GT version

According to Breckenridge et al. (2012) the researchers, and even more so novice PhD students, should be aware of the reasons that led them to choose the X or Y school of thought or methodological path based on ontological and epistemological criteria. Breckenridge et al. (2012) exhort GT researchers to be “clear and consistent in their choice of methodology, following one path rather than engaging in a methodological pick and mix” (Breckenridge et al., 2012:69).

Both ontological and epistemological divergences among Anselm Strauss, Barney Glaser and Kathy Charmaz (an ex-PhD student of Barney Glaser) led to different versions of what was initially named as GT. If we take a closer look again at GT, we will see that there are not only ontological incompatibilities that gave birth to different versions but epistemological ones as well. For example, the great difference between Charmaz and the supporters of *classic* GT, is of an epistemological nature. In particular, Charmaz, as an interpretivist, supports that interpretive theory ‘assumes emergent, multiple realities, indeterminacy, facts and values as linked, truth as provisional and social life as processual (Charmaz, 2014:231). In contrast, theory from a positivist’s perspective “seeks causes, favors deterministic explanations and emphasizes generality and universality” (Charmaz, 2014:229). As a *relativist*, Charmaz (2000) made her ontological position more explicit stating, “data do not provide a window on reality. Rather, the discovered reality arises from the interactive process and its temporal, cultural and structural contexts” (Charmaz, 2000:524). These epistemological divergences led Charmaz to shape and develop her own version of GT i.e. the *constructivist* approach.

To sum up, the current PhD thesis draws upon Charmaz's (2014) GT approach because I hold the same ontological and epistemological perspective as her and these are presented in the following abstract:

"We are not passive receptacles into which data are poured. We are not scientific observers who can dismiss scrutiny of our values by claiming scientific neutrality and authority. Neither observer nor observed come to a scene untouched by the world. Researchers and research participants make assumptions about what is real, possess stocks of knowledge, occupy social statuses and pursue purposes that influence their respective views and actions in the presence of each other. Nevertheless, researchers, not participants, are obligated to be reflexive about what we bring to the scene, what we see, and how we see it" (Charmaz, 2014:27)

5.3 Sampling technique

5.3.1 Purposive sampling

The total sample of sixteen interviewees encompassed a group of eight doctors (three pediatricians, one diabetes expert, one gynecologist, one dentist, one ophthalmologist and one specialist in infectious diseases) and a group of eight mental-health experts (two dramatherapists, two psychiatrists, and four psychologists-psychotherapists oriented in the *psychodynamic* school of thought). This sample selection was built on three criteria.

Firstly, the use of ICT devices and applications (both synchronous and asynchronous) for remote communication with their patients/clients for implementing any medical act either in substitution of or supplement to the traditional face-to-face encounter. In other words, what brings all these healthcare experts under the same 'sampling umbrella' is my participants' statements that communication via any mode of ICT is an integral part of their professional routine on a daily basis. I did not set any quantitative criteria such as hours of communication via telephone on a daily basis for excluding any potential research participant. Instead I relied on my interviewees statements such as "*my mobile phone rings all day long [...] receiving phone calls from patients even during the night*" offered by Pedia2 or "*I used to receive a lot of photos and videos from parents all the time*" (Pedia1) verified that communication via ICT is part of their professional routine. Similarly, MHE1 underlined that more than half of her weekly psychotherapeutic sessions (7 out of 15 on average) are implemented via Skype.

Secondly, what makes this group of healthcare experts concrete are their claims to professional expertise which, as the literature supports, implies trust. According to patient-to-doctor literature, trust plays a vital role in the healthcare provider/patient relationship irrespective of whether the former is a doctor oriented in western medicine, a MHE, a nurse or even the shaman of a tribe (*Toafa et al, 1999*).

It is reminded that the aim of the current thesis is not to focus on a specific health-care occupation (i.e. only doctors, diabetes experts, gynecologists, nurses, psychiatrists, psychologists etc.). Rather, it aims to identify possible nuances that occur in the patient-to-health expert relationship through the substitution of face-to-face encounters with remote communication, with particular interest in how the element of trust plays a role.

Finally, none of the healthcare experts interviewed are employees in either a public or a private hospital. All are self-employed and thus not subject to any corporate or organizational code of conduct. In other words, they utilize ICT at their own discretion, based on their own professional needs and on very personal interpretations of the *Greek code of medical conduct (N3418/ 2005)*, which makes no clear reference to any remote mode of communication between doctors and patients.

To summarize, what qualifies the sample of participants to be described as coherent, is that (a) all of them have first-hand experience of remote communication via ICT with their patients on a regular basis and (b) all of them attract their patients' trust due to their healing abilities. Finally, what all research participants have in common is that each one of them is self-employed.

On the healthcare experts' matrix (p. 248), are provided details about healthcare experts' professional experience in terms of years and professional qualifications. Moreover, the matrix provides the ICT that they employ for remote communication with their patients as well as details about or main and follow-up interviews in terms of duration and mode of communication.

5.3.2 Theoretical sampling

In sharp contrast to quantitative research, *sample size* in qualitative research has always been a topic attracting theoretical controversy and debate. The literature on sampling techniques in qualitative research reveals that there is neither a ‘rule of thumb’ nor a ‘golden number’ that should be blindly followed. As Mason (2010) notes, a skilful interviewer who has conducted ten interviews, may be more productive in terms of data analysis than a novice who has conducted 50 interviews. Thus, the question that should be answered during the research design phase are “*when should I stop data-gathering?*”.

In GT the researcher cannot define the sample size in advance. The answer given by *constructivists* is that researchers should stop the data-gathering process ‘when gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical strategies’ (Charmaz, 2014:213). In the GT jargon, that stage is often called *theoretical saturation*. Though the issue of *sample size* in GT appears to be mapped in every detail, it still remains tricky and open to various interpretations. Urquhart (2013) urges researchers to stop data-collection when no new concepts emerge from the data, while Charmaz (2014) contests that conception underlining that *theoretical saturation* does not refer to “*nothing new happening*”. In other words, it is implied that some researchers often proclaim theoretical saturation at a very early stage (Morse, 2002). That is why Charmaz (2014) invites researchers to be self-critical about *theoretical saturation* at each stage of their research.

5.3.3 A memo regarding theoretical sampling

At this point I consider it important to demonstrate through a *memo* how I experienced issues in sampling in compliance to my commitment for thorough description in methodological choices (Guba, 1981).

My studies and papers in finance and capital markets are interwoven with the tradition of quantitative research. Although it is recognized that econometric models are not perfect, since they often rely on fragile hypotheses (i.e. investor’s make rational decisions), sampling is rarely considered an issue of controversy. There is no doubt that, over the years, GT has been refined and has finally evolved into a highly sophisticated research tool capable of giving birth to emerging theories, or even better, to concrete ones. For example, the arguments and rationale

underpinning the practice of *theoretical sampling* have influenced a number of social researchers beyond the boundaries of the grounded theorists' territory.

However, achieving *theoretical saturation* through *theoretical sampling* is often based on the fragile hypothesis that (a) research participants face no time constraints, (b) they would welcome any invitation for a follow-up interview and (c) resources in terms of number of participants are inexhaustible. Nevertheless, although Charmaz's (2014) thesis that researchers should stop data-collection "when gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical strategies" (Charmaz, 2014:213) remains clear and well documented, it still raises a small number of questions. The first emerging question is the following: Who can finally assess that "*any fresh data no longer sparks new theoretical insights*", given that neither do all researchers observe the themes under study through the same 'looking glass' nor do they have the same interviewing and analytical skills? It is important to remember that there is no 'shared reality' for *constructivists*. Furthermore, who can tell, in the end, that "*gathering fresh data no longer reveals new properties*"?

Moreover, *theoretical sampling* might not be feasible due to objective constraints associated with money, time or even sources of information (i.e. potential interviewees' availability). For example, how possible is it for researchers to implement theoretical sampling when approval of institutional review boards is demanded each time it is necessary to revisit research participants? How possible is it for researchers to implement theoretical sampling when accessing research participants is considered as an issue due to factors associated with vulnerability or accessibility (prisoners, mental health patients, etc.)? Similarly, Wiener (2007) mentioned that *theoretical saturation* is a judgement not far distanced from practical constraints, such as time or money. Though *member-checking* is considered a technique that offers the potential to achieve higher levels of *theoretical saturation*, due to the lack of accessibility to an additional number of research participants, it still ignores the aspect of accessibility, since it takes it for granted that research participants interviewed will always be available for one more round of interviews.

For example, during the research design stage of my thesis, I managed to get a positive response for interviews with approximately 25 healthcare professionals who had underlined that remote communication with patients, strictly for medical purposes, was an integral part of their daily professional routine. All interviewees had been assessed as rich pools of information. In classrooms of research methods, the number of twenty-five to thirty interviewees is often recommended as a 'rule of thumb' i.e. the number of interviewees likely to gain both editors' and examiners' respect. Finally, 16 out of the total of 25 healthcare professionals were interviewed.

I hold the view that when faced with such theoretical dead ends, researchers should attempt to get the most out of their interviewees in terms of data, especially when interviewees have expressed concerns about the estimated duration of the interview. In the case of my PhD thesis, I sought to have a follow-up interview with all my interviewees, even if done through focus questions sent by email, in order to respect their professional and personal time. From the viewpoint of common sense, abandoning research projects in the light of such limitations should not be considered an option, especially in cases where energy, financial and temporal resources have already been invested. Though the criteria of *theoretical saturation* may still remain unfulfilled, this does not necessarily mean that no new knowledge has been brought to light, especially in cases of exploratory studies, such as the one used in the current thesis, where there was no prior knowledge. Quoting Thornberg (2012):

“judging saturation is always tricky and thus risks foreclosing analytic possibilities and constructing superficial analyses” (p. 252)

To sum up, instead of pretending that *theoretical saturation* has been achieved, and, thus, a concrete theory grounded in first-hand data is a fact, I hold the position that developing a theory should not be treated as an obsession, even for grounded theorists. In social sciences, new knowledge and theories are brought, challenged and finally tested by researchers through the years. In that sense, I hold the view that GT, similar to any other research tool, should aim at shedding light on unexplored areas and ideally contributing to knowledge through theory development. In other words, theory development should not be considered a synonym to knowledge contribution. In that sense, I would support that the current thesis casts light, for the first time, upon previously unexamined aspects of remote communication between

patients and healthcare experts (i.e. doctors and mental-health experts) from a trust perspective. At the same time, this study opens the path to the formulation of a theory grounded in primary data in the near future regarding the role, mechanics and value of trust in the light of over-the-counter patient-healthcare expert remote communication.

5.4 Data collection

5.4.1 Intensive interviewing

The exploratory nature of the research question imposes a qualitative approach rather than a quantitative one. In-depth *intensive interviews* were employed for data collection as the most popular and effective research tool on trust in healthcare (Goudge and Gilson, 2005). *Intensive interviewing* is a term often used by Charmaz (2014) to describe the ‘interactional’ space that researchers ought to build in order for the interviewees to feel safe and narrate their personal experience. Charmaz (2014) defines *intensive interviewing* as the interview technique which:

- Focuses on research participants who have first-hand experience of the studied concept who, in my case, are health-care professionals.
- Aims for the in-depth exploration of interviewees’ personal experience through *story telling*.
- Is grounded in open-ended questions.
- Aims to obtain the most detailed answers as is possible.
- Invests a lot in the follow-up technique, especially when unanticipated issues, ideas or areas of inquiry arise
- Emphasizes the way that research participants’ experience and assign meanings to concepts and events.

Indeed, the application of *intensive interviewing* technique, as this has been defined and described by Charmaz, 2014), offered me the potential to focus on healthcare private practitioners who had first-hand experience over the practice of remote communication with their patients through open-ended questions in order to get the richest data as is possible. I recognize that the follow-up technique was fruitful in cases when controversial issues or statements emerged though it was difficult especially for doctors to commit and finally

implement a follow-up interview. Indeed, the application intensive interviewing, as this has been defined and described by Charmaz, 2014), offered me the potential to focus on healthcare private practitioners who had first-hand experience over the practice of remote communication with their patients through open-ended questions in order to get the richest data as is possible. I recognize that the follow-up technique was fruitful in cases when controversial issues or statements emerged though it was difficult especially for doctors to commit and finally implement a follow-up interview. However, it is worth noting that, although the researcher might have the best of intentions for collecting as much data as possible, practical limitations, such as doctors' limited availability in terms of time, should be taken into consideration.

5.4.2 Issues in data-collection

As has already been mentioned, recruiting and finally interviewing doctors was a hard task for two reasons:

Firstly, they had very limited time for interviews, which sometimes did not exceed forty-five minutes. Follow-up interviews were hard to schedule. It is underlined that according to my initial estimations, I should have had easily accomplished 15 interviews with doctors. At the end of the day, the total number of interviews with doctors was less than ten. Cancellations often took place because they had emergency cases to resolve while many times during our interviews their mobile phone would ring, interrupting the flow of our interview. Most phone calls were from patients who called for a variety of reasons. On the one hand, that was a constraint because as mentioned before, emergency phone calls would interrupt the flow of the interview. On the other hand, after these interrupting phone calls, I would ask questions about the phone calls themselves. That was a strategy for turning limitations to opportunities. *Secondly*, it became clear to me that I would not have ample time for interviewing doctors and thus I should ask fewer introductory, open-ended questions and, after a point, more guided questions. That was why after my second interview with doctors I started sending more descriptive, pre-interview material about the topic of my research along with a couple of questions such as “*what ICT do you employ when you communicate remotely with your patients?*” or “*what sort of data do you receive?*”. After my first two interviews with paediatricians when I detected that both (a) the person sending the data (in terms of

trustworthiness) and (b) the quality of data themselves seemed to play a role in their decision-making process, I added to my pre-interview questionnaire the question “*I was wondering how do you verify that the data transferred by your patients in remote are accurate and thus valid?*”.

Nevertheless, recruiting mental health experts, psychiatrists included, was not a challenging project. They responded positively to my requests for interviews, were on-time for our interviews, as well as being very keen to give interviews. This in contrast to the doctors who would cancel our appointments up to five times and re-schedule them at a future date. It is underlined that all the mental health experts responded in a positive way to my invitation for interview while the response rate of the doctors was less than 50%. Lower response rates on behalf of doctors could be also attributed to money matters, given that a 15 minutes session in Greece might be equal or even double to a wage. My interviews with mental health experts were rarely interrupted by patients’ phone calls. I would attribute their consistency to the fact that mental-health experts have a more structured schedule where sessions last either 45 minutes or 60 minutes with a time-gap of 25 minutes between. Interviews with mental health experts would take almost 60 minutes without a need for them to end our interview as soon as possible. There were cases where follow-up interviews would take more than half an hour creating, in a way, an asymmetry in terms of data offered between healthcare professionals.

5.5 The GT data-analysis toolkit: coding, memos and constant comparison

The analysis of my data has been implemented through *initial* and *focused coding*. During the *initial coding* stage, I would name each line or segment of data (rarely each word) with a code i.e. a spontaneous word or a phrase. However, it is worth underlining that there were many times, especially in the course of my first interviews, when I revisited my transcripts and attached a different initial code to a line or segment of data. The initial coding process became easier as the collection and analysis of my data progressed. *In vivo* coding, used to define words, phrases or terms used by interviewees themselves, were applied mostly during the analysis of data that came from the group of mental health experts. My experience of the stage of initial coding revealed that *in vivo* coding, in contrast to any other coding technique, offers a greater possibility to view the phenomenon under study through the eyes of the research participant compared to any other initial coding technique. It is underlined that *in vivo* codes were chosen to represent a larger segment of data and finally offer their name to *focused*

codes. In particular, during the second stage of data-analysis I grouped initial codes under a new label that I call a *theme*. While initial codes are necessary to organize a group of primary, secondary, meaningful or even irrelevant-to-the-research-question bunch of data, focused codes have the advantage to offer meaning to words, lines and phrases coded spontaneously. Finally, a selected group of focused codes should be able to represent our research participants' reality *contaminated*, of course, by the researcher's perspective.

In the course of the initial and focused coding stage I kept a number of notes as bullet points, mostly in the form of "who", "how", "why" or "what" questions. That sort of question was considered necessary in order to give meaning to my data. For example, one of the statements that played a key role in the direction my thesis took was the following, made by Pedia1 at the end of our first interview:

"I will use data sent from a parent I trust in a completely differently way than data sent by someone I know who is in search of an easy solution." (Pedia1)

It was obvious to me that Pedia1 had patients he trusts and others he did not. Moreover, it was obvious to me that the ones he did not trust would search for easy solutions. So, the questions that emerged were "*what is the profile of the patient he trusts?*" or "*why is searching for an easy solution a matter of trustworthiness for Pedia1?*". Those kinds of questions were recorded, not only in order to get an answer in a follow-up interview, but also to offer a direction to my next interviews. That technique is defined as *memo-writing* and is considered by grounded theorists as a necessary tool for the progression of analysis. In my thesis, *memo-writing* often took a variety of forms such as flow charts, questions, notes or spontaneous thoughts. It is worth noting that I did not use memo-writing in order to demonstrate compliance with the strict line of GT. Instead, I employed *memo-writing* because it was not possible to record, manage and finally utilize in a creative manner, a number of ideas which emerged during both the earlier and later stages of my analysis. For example, the whole 5.3.3 paragraph is an expanded version of memos with regard to methodological issues.

Finally, all tools mentioned above, such as the one of *theoretical sampling*, coding techniques or *memo-writing* were employed in order to support the core tool of GT which is the *constant-comparison* method. Based on first-hand experience, I would define the *constant-comparison*

method as a process where bits of data (i.e. words, lines, phrases, events) are compared in a continuous way with other bits of relevant data either (a) within a single interview (see initial coding), or (b) between different interviews, as well as (c) between different groups of healthcare professionals at a *themes* level. For example, a form of *constant-comparison* of data within the same interview is the process of initial coding which results in focused coding. In more detail, it is the *constant-comparison* method that brings a large group of initial codes under the same code or, respectively, under totally different codes.

5.6 Designing a trustworthy PhD thesis

The value of qualitative research in terms of *valid* and *reliable* results has always been a challenge and a topic for continuous debate within the research community. *Validity* in qualitative research has invariably been disputed by *positivists* and social scientists coming from the school of *objectivism*. Though a significant number of cornerstone papers and books has been published with regard to the issue of trustworthiness in qualitative studies, it seems that ‘the problem of rigor in qualitative research’ (Sandelowski, 1993:1) still remains an issue of controversy/debate. My experience as a PhD candidate is that the issues of *validity* and *credibility* are still evolving. Though Guba (1981) produced, in a well-documented manner, a toolkit for qualitative researchers capable of supporting the quality of their research output, there are still some issues under consideration.

Guba (1981) built his trustworthiness model of qualitative research on four major pillars: *a) credibility, b) transferability, c) dependability* and *d) confirmability*.

5.6.1 Credibility

In the *naturalistic paradigm*, Guba prefers the term *credibility* instead of *internal validity* (often met in quantitative studies) which falls into the broad category of the *rationalistic paradigm*. *Internal validity* describes how consistent the findings are with reality, given that reality, knowledge and truth for both positivists and realists are accessible. This view sits in sharp contrast to my ontological and epistemological views which fall under the theoretical umbrella of the *naturalistic* paradigm. The question often set by qualitative researchers and PhD students in the light of their *viva voce* is “*how can I empower the credibility of a constructivist’s GT study where the working hypothesis of a single reality is replaced by the ontology of multiple*

realities?". According to Sandelowski (1986), the *credibility* of a qualitative study depends on the capacity of the researcher either to describe or to interpret in the most accurate way, the examined human experience. Though Guba (1981) suggested a number of tools such as *persistent observation*, *peer debriefing*, *member checks* and *triangulation*, I relied mostly upon *triangulation* taking into account practical constraints such as time or levels of feasibility. A "variety of data sources, different investigators, different perspectives (theories), and different methods are pitted against one another in order to cross-check data and interpretations (Denzin, 1978)" (Guba, 1981:85). Within the framework of the current thesis, I apply *triangulation* through a review of the limited yet available literature in the light of my findings.

For example, when the profile of the trustworthy patient began to take form, I searched for academic papers which studied the aspect of mutuality in the patient-doctor relationship. Surprisingly, I found out that (a) there were no more than eight papers implying that the patient-doctor relationship is based on mutual trust (Thom et al., 2011; Cook et al., 2004; Calnan et al., 2006; Thorne and Robinson, 1988; Miller, 2007; Rogers, 2002; Jain et al., 2006; Merrill et al., 2002) and (b) that it was only Thom et al., 2011 who attempted to develop and validate a measure of the doctor's trust in the patient. That sort of triangulation not only verified that I was contributing to knowledge in actual terms, but moreover that other scholars have offered a similar perspective of the phenomenon under study. To sum up, triangulation is present in my thesis throughout the discussion of my findings with the limited, yet available, literature from the field of patient-doctor relationship or computer-mediated communication studies. It is noted that I did not try the member-check technique, not only because it was not possible to contact my research participants for a third round of interviews, but moreover because I considered it as incompatible to my ontological assumptions. In particular, asking each one of my interviewees to verify my research output is equal to asking from them to establish the validity of my very personal interpretation, which is rather impossible. Similarly, Sandelowski (1993) has expressed the view that *member-validation* should be probably approached as a threat to validity rather than a means for demonstrating validity.

5.6.2 Transferability

In qualitative inquiry, *transferability (or fittingness)* is a term suggested by Guba (1981) as a substitute for the terms *external validity* or *generalizability*, which are used in rationalistic

inquiry. These latter terms are used to describe whether it is feasible to make generalizations about larger population samples or the level to which the findings can be applied to similar environments, contexts or groups of population. Guba suggested a number of tools and techniques in order to verify transferability during a study such as *theoretical/ purposive sampling* and collecting thick descriptive data. Guba (1981) also suggested the *development of thick description* of the context as a useful tool for verifying transferability after the study is completed. The limited number of participants did not allow me to check whether a level of theoretical saturation had been achieved as a result of a successful theoretical sampling process. However, I expect that (a) the detailed description of the *purposive sampling* process along with (b) the collection of thick descriptive data and (c) the development of thick description of the context, offer the potential reader, editor or examiner the opportunity to assess my thesis' transferability to similar contexts. To sum up, transparency and thick description were the keywords I bore in mind throughout the writing process of my thesis.

5.6.3 Dependability

In the rationalistic paradigm, the instrument of *reliability* is used to measure the *consistency* of the results produced by a quantitative study. For example, once an econometric or statistical model, which is employed in a quantitative study, provides the same results even when applied to different people, different data or in a similar context, then it is said that the data and the study are consistent. For Guba (1981), *consistency* is not considered as a prerequisite for the attainment of credible results. Furthermore, he proposes that instead of *consistency*, naturalists should alternatively make use of the term *dependability*, which brings together elements both of the “stability implied by the rationalistic term *reliable* and the trackability required by explainable changes in instrumentation” (Guba, 1981:81). But how can the dependability of the study be measured, assessed or examined when the instruments under scrutiny are both the researcher and the participant? Techniques such as that of *audit trail*, are suggested for the strengthening of the trustworthiness of each qualitative study that falls into the broad category of the naturalistic paradigm. In compliance with Shenton's suggestions for achieving *dependability* (2004):

1. Rich information and thick description are provided throughout the research design and implementation of the current thesis

2. Rich information and thick description are provided through operational details of data gathering.

It becomes apparent that both thick description and transparency are the keys for ensuring dependability. However, terms such as *thickness* and *transparency* are, by default, social constructions and thus subject to the hermeneutics of each subject.

5.6.4 Confirmability

Finally, In the quantitative setting the issue of *neutrality*, or else the *objectivity* achieved through sophisticated methodological techniques, is often addressed. In other words, objectivity implies that a distance between the researcher and the phenomenon under study is achievable and that unbiased results are feasible. This positivistic-quantitative approach is epistemologically incompatible with the constructivist's approach followed in the current thesis. While qualitative researchers recognize the value of the distance between the researcher and the participant, they attempt to increase the value of the findings by minimizing that distance in sharp contrast to what quantitative researchers located in positivism do. Guba suggested *triangulation* and *practicing reflexivity* as two potential means for assessing *confirmability*. Guba (1981) described the process of *practicing reflexivity* as the one where the researchers reveal to their audience "the underlying epistemological assumptions which cause them to formulate a set of questions in a particular way, and finally to present their findings in a particular way" (Ruby, 1980, cited in Guba, 1981:87). I would consider that a major effort has been made throughout this PhD thesis to unravel and reveal both my ontological and epistemological assumptions in a way that allows the potential reader, editor or examiner to assess my thesis in terms of confirmability. With regard to the aspect of the distance between the researcher and the phenomenon under study (or even the participant him/ herself), I would support that the fact that both my professional and academic experience are not related to that of healthcare and telecare offer me a "safe distance" from the phenomenon itself.

5.7 Reflections on methodological issues

5.7.1 Defining trust as an issue of concern: a personal note

Goudge and Gilson (2005) advised researchers studying trust that it is of great importance to work on the establishment of a well-grounded definition that will “ensure that respondents’ answers refer to the form of trust under investigation” (Goudge and Gilson, 2005:1439). Though trust has been a popular research subject in a variety of scientific realms (i.e sociology, psychology, management, computer-mediated communications, human-computer interaction, patient care etc.), it is still considered by many scholars as difficult to define and so to investigate (Goudge and Gilson, 2005). Indeed, the absence of a well-grounded and concrete definition is often underlined by many scholars of trust as a limitation (Goudge and Gilson, 2005; Blomqvist, 1997; Giddens, 1990, Young and Wilkinson, 1993). Similarly, Mayer et al. (1995) recognized the lack of a universal definition as a limitation in organizational and management studies that focus on trust. Young and Wilkinson (1993) from a similar point of view, underlined that existing definitions are of limited use because they focus on cataloguing the elements associated with the presence of trust. In other words, defining trust adequately is often demonstrated as an essential precondition for investigating it either in a qualitative or a quantitative context.

Nevertheless, ontologically as a *relativist*, I would not support the view that there should be a universal definition of trust. In compliance with my ontological perceptions, I hold the view that there potentially should be as many definitions as the world population since trust, among other concepts or ideas, is subject to a very personal interpretation. Instead of perceiving the lack of a commonly accepted definition of trust as a limitation, I would regard it as a motive for exploring trust perceptions in different geographical areas, religious or professional contexts such as the patient-doctor relationship.

5.7.2 The translation dilemma in coding

One of the greatest challenges that emerged during the research design stage was that of handling the interview transcripts in Greek. Here I underline that all interviews were conducted in Greek given that the sample consisted of Greek health-care professionals. The dilemma that arose was whether I should run the *coding* process of transcripts in Greek or English. Translating interview transcripts from Greek to English was calculated to be infeasible both in terms of time and money, even in the case of employing a professional translator. Though Welter and Alex (2012) suggested that all their interview transcripts on trust issues were

translated into English in order to allow for a joint analysis of the data gathered, they noted that:

“Naturally, the accuracy of the English protocols was influenced by the language skills of the respective national research teams and/or their translator, thus in the worst case ‘distorting’ our interpretations of trust-related issues” (p. 57)

They clearly implied that a risk of distortions in interpretation was an underlying issue. In other words, their experience showed that there are always great possibilities for interpretations and meanings to be distorted due to mistranslation. That is a risk that I wanted to avoid at any cost. Consequently, I made the decision not to translate the interviews from Greek to English but rather to run the whole coding process on the Greek interview transcripts. Finally, I decided to translate and import into my thesis only these abstracts that I would consider as ‘key’ since they had the potential to communicate to the reader my interviewees’ key statements and positions. Excerpts sent for translation were anonymized and scrutinized each time I got them back in order to check if the translations distorted my interviewees statements and thus meanings.

5.8 Interacting with my literature review

The idea that a researcher should be defined strictly as a *grounded theorist* only when he has managed to delay the literature review to avoid *contamination*, is still a popular issue for debate both in lecture theatres and at research conferences. As a *relativist*, I support that it is not feasible for such a dictum to stand by itself. Within the framework of this section, I argue why avoiding, ignoring or, worse still, pretending to ignore the literature review, includes great risks for PhD candidates.

In my PhD thesis, I explore how healthcare professionals experience remote communication with their patients, through the lens of trust. In other words, I am keen to learn, through the healthcare professionals’ perspective, what is the role of trust when both parties communicate by any ICT instead of the regular face-to-face session either at the doctor’s or patient’s premises. On the one hand, I could support that I maintain a safe distance from the phenomenon under study as I do not work in the health sector. On the other hand, that “safe distance” includes a number of risks. As Thornberg (2012) mentions “ignoring established

theories and research findings implies a loss of knowledge” (Thornberg, 2012:245). Consequently, it was an imperative need, even from the very early stage of research design, to be aware of the literature regarding trust’s properties and the patient/doctor relationship.

However, prestigious scholars from the field of sociology have explicitly expressed the concern that technological developments could not leave untouched the element of trust that is the core of the patient-to-doctor relationship (Beck, 2006; Giddens, 1990; Luhmann, 2000). Moreover, a very limited though relevant literature review indicates that computer-mediated communication has strong potential to empower the patient’s trust in the doctor (Andreassen et. al, 2006; Simpson et al., 2005). Nevertheless, a positive outcome is not always guaranteed given that such practices demand further and careful consideration (Andreassen et. al, 2006). Sociologists’ concerns as well as slight indications coming from the limited literature review, “contaminated” my research interest and thus my research question.

However, during the stage of data-collection, key codes started to emerge such as that of *mutual trust* and the *trustworthy patient*. Immediately after these concepts began to emerge, I revisited the literature in order to check if there was any indication that the patient-doctor relationship was one based on *mutual* trust rather than one-way trust (patient’s trust in doctor). Only eight papers detected implied or even discussed the aspect of mutuality and the concept of the trustworthy patient without mapping in detail his/her profile (Thom et al., 2011; Cook et al., 2004; Calnan et al., 2006; Thorne and Robinson, 1988; Miller, 2007; Rogers, 2002; Jain et al., 2006; Merrill et al., 2002). It was of crucial importance for me to be aware that I had already somewhat started contributing to knowledge. “[T]he researchers have to recognize that what might appear to be a totally new idea to them in terms of “innovative break-through” in their research might simply be a reflection of their own ignorance of the literature (Lempert, 2007)” (Thornberg, 2012:245). Finally, it was only Thom et al. (2011) who attempted to develop and validate a measure of doctor trust in the patient. Thus, it was clear to me that, in the light of my research question, I had the opportunity to contribute to knowledge offering a better understanding of the *trustworthy patient’s* profile.

5.9 Provision and awareness of ethical issues

Ethics in social research and science have always been a primary concern for academia. Questions such as “*what constitutes ethical behavior?*” or whether “*knowledge should be pursued at any cost?*” are fundamental and challenging for each social researcher who rejects the maxim that researchers should seek the truth at any cost. Lincoln and Guba’s (1989) query about whether there is any guidance to be given on ethical research, reflects the perplexity of the social researcher standing in front of the multifaceted and fuzzy notion of *ethics*. In my opinion, social researchers ought to be aware of the hazards that could possibly be accommodated in their own research tools and customize policies, strategies and practices provided by universities and research handbooks to the needs and challenges of their own research methodology. Nevertheless, I hold the view that there are some fundamental principles that should be blindly followed in all cases. The principles implied are: (a) commitment to the participant’s psychological and physical safety, (b) respect of the practice of *informed consent*, (c) transparency as well as (d) respect of the principles of privacy and confidentiality. It is highlighted that respecting privacy and confidentiality is not unconditional especially in the light of a crime or criminal act confessed.

According to the first principle, the research subject should not be harmed or even placed at any kind of physical or psychological risk. It is well understood that the broad category of social research is not highly related with physical risks. Instead, psychological risks often appear in social research especially when the interviewees are individuals who could be considered as vulnerable such as patients, people who had near death experiences or people recovering from shocking events. With respect to my research participants’ physical and psychological safety, it was made clear at the *consent form* demonstrated at the appendices section (p. 246), that their participation is voluntarily and thus they are free to withdraw at any time without giving reasons. In other words, it was made it clear that it was not my intention to press any points that appeared to distress or annoy them.

Furthermore, I hold the view that social researchers should not forget that it is of high priority to allay any suspicions that interviewees may have against them. Unless there is a well-grounded, trust-based relationship between the interviewer and the research participant, it is not possible to obtain any rich data. The practice of *informed consent* comprises a safety net often employed by social researchers in order to establish a trust-based relationship with

participants. An *information sheet for participants* attached to a *letter of consent* had been sent by email in advance to each of my interviewees. The *consent form*, as well as the whole letter of information for participants, were sent not only in order to attract their interest but mainly in order to give them an outline of my interview's main themes and minimize, if not eliminate, any concerns regarding lack of transparency. In other words, the *consent form* served as a point of reference between what has been agreed and was finally proved to happen during the interview.

Moreover, my consent form explicitly communicates to my interviewees that actions have been taken so as to be consistent with the principle of privacy and confidentiality. It is worth emphasizing at this point that all participants had been informed that their names would not be used throughout my thesis. Instead I invented a system of producing *nicknames* based on their expertise. Nevertheless, it is underlined that respect of the principles of privacy and confidentiality is *not* unconditional. All participants had been informed in advance of the interview that the principle of privacy and confidentiality would be cancelled in the case of declaring that they had committed or that they were intending to commit a criminal action either against other peoples' lives or against other peoples' assets. However, none of my research participants expressed any concerns since all of them are healthcare experts and thus aware of fundamental principles of medical and research practice such as the one of patient's privacy and confidentiality.

Chapter 6

The trustworthy patient (carer)

Within the framework of Chapter 6 I introduce, explore and unravel the under-researched aspect of *mutuality* in the patient-healthcare

expert relationship and, thus, the theme of the *trustworthy patient (carer)*. Moreover, the current chapter links the construction of the *trustworthy patient (TP/C)* with the extended code of the healthcare experts' *risk perceptions*, as well as with a web of *skills* that constitute property of the TP/C. It also provides a detailed taxonomy of the *medical data* theme and how this is associated with TP/C's communication skills. Emphasis has been placed on the patient-MHE *trust paradox*, demonstrating, in particular, that though MHEs recognise the value of mutuality in their trust-based relationship with their patients, they do not recognise the concept of the *trustworthy patient*. Chapter 6 ends with an integrated diagram (web of trust) that brings together the TP/C's communicational skills, the healthcare expert's *risk perceptions* and the theme of medical data as core elements of "trust in a patient".

6.1 The patient-healthcare expert relationship: an indisputable bond of trust

I intentionally started my interviews by asking healthcare professionals how much they value trust in their relationship with their patients, though the entire body of the patient-physician relationship literature review verifies that trust is an indisputable element of this bond. The question was posed so as to offer physicians the opportunity to express themselves, ensuring that each one of them shared the view supported by the existing literature review regarding the nature and properties of the patient-physician relationship. Nevertheless, implementing my research project based on hypotheses –even if these are derived from the relevant literature review- is incompatible with the exploratory nature of my study. Indeed, all participating physicians emphatically stated that trust, with regards to power, is the key-attribute of such an asymmetric relationship, thus, verifying the findings of the existing patient-physician literature (see Table 6.1a). Similarly, physicians indicated that their relationship with their patients' carers is one based on trust, too (see Table 6.1b).

Similarly to physicians, the total number of MHEs interviewed highlighted the critical role trust played in their relationship with their patients. Initially, trust was found to be a prerequisite condition for the patient-to-MHE relationship to be *functional*. As Psych1 stressed:

"...nothing is going to work in the absence of trust..." (Psych1)

Trust is also considered by MHEs as a prerequisite condition for activating *patients' self-disclosure*, which is considered one of the key-aspects of effective therapy.

“If the other person does not trust us, how are they going to open up?”
(MHE3)

Similarly, for MHE6, trust is considered a prerequisite condition in order for MHEs to honestly share their thoughts with their patients:

“trust is a necessary component, a necessary structural element, so that there may be honesty and all the more information from the supporter to the person being supported” (MHE6)

Trust is also associated with the positive outcome of the therapeutic process (*effectiveness*).

As Psych1 stressed:

“trust is a necessary component, a necessary structural element, so that there may be honesty and all the more information from the supporter to the person being supported” (Psych1)

Similarly, MHE1 associated trust with the positive outcome of the therapy:

“healing is not possible without trust in the therapist” (MHE1)

Excerpt 6.1 reveals, in the most emphatic way, the critical value of *trust* in the patient-to-MHE relationship.

Interviewee	The importance of trust in the patient-doctor relationship
Pedia1	<p><i>"If there is no trust -which is something built over time-, one should change one's doctor."</i></p> <p><i>"[The parent] who doesn't trust you will stop being your client, and even if he/she doesn't leave, you must push him/her away because that is not good either for you or for him/her [to hold on to this relationship]."</i></p>
Pedia2	<p><i>"Trust plays a huge role! I believe that once a mutual trust-based relationship exists, the patient's health keeps improving [...]; trust plays a huge role for the outcome and therapy of a patient, regardless of his/her age."</i></p> <p><i>"Everything is a matter of trust, which means that you must earn this trust. Once you earn it..."</i></p>
Ophthalm1	<i>"At the ophthalmology clinic where I used to work, I was helping my consultant who was an expert in Glaucoma; yet people who had s serious problem, even though there was no one else to perform the operation, they would not ask him to operate on them. This was a matter of perception and of not having created a relationship of trust."</i>
ObGyn1	<i>"A trust based relationship is very important, because the patient herself has a stronger sense of safety and certainty, while I, personally, feel my treatment and advice will be more effective [...] patients who demonstrate higher levels of trust than patients who tend not to trust, may have a better outcome."</i>
Diab1	<i>"It is very important to be trusted by the patient. This is where it all begins; of course, if they don't trust you, they will stop coming to you and this is clear."</i>
Dent1	<i>"You have to earn the patient's trust first, before they let themselves in your hands."</i>
Phys1	<i>Trust is the most important thing in the patient-to-doctor relationship</i>
Pedia3	<i>"It is common for me to receive mums to my office who tell me things like "you know, my mother-in-law tells me to do that, but I will follow your instructions!" or "my mother told me to do the other thing and I do it!" As you can see, mum let us, doctors, enter their home, get to know their relationship with their husbands, their children, their own mums and mothers-in-law. In other words, the paediatrician-to-mum relationship has to be a trust-based relationship."</i>

Table 6.1a
The importance of trust in the patient-physician relationship

Interviewee	<i>The importance of trust in the carer-doctor relationship</i>
Pedia1	<i>"There cannot be a proper relationship between a child and the paediatrician without parents' trust. It's a relationship doomed to end. Something will go wrong."</i>
	<i>"Of course, the parent-paediatrician relationship is a two-way road. It is not only about us, but also about the guardian of the child."</i>
Pedia2	<i>"the paediatrician has to 'win' both the kid and the parents, which means that communication is extremely important in both directions. If one direction fails, it is very likely that the relationship will not last; it will soon fail!"</i>
Diab1	<i>"You have to understand that we often have to do with elderly persons with dementia, either incipient or full-blown. These are cases when the family member has to be reliable, because it is them who transmit the relevant information."</i>
Phys1	<i>Trust in the carer-to-doctor relationship plays a much more important role than that of patient-to-doctor. This is because one has to convince a third party (not patients themselves) about the necessary decisions. Trust is much more important in the carer-to-doctor relationship than the patient-to-doctor one!</i>
Pedia3	<i>"It is common for me to receive mums to my office who tell me things like "you know, my mother-in-law tells me to do that, but I will follow your instructions!" or "my mother told me to do the other thing and I do it!" As you can see, mum let us, doctors, enter their home, get to know their relationship with their husbands, their children, their own mums and mothers-in-law. In other words, the paediatrician-to-mum relationship has to be a trust-based relationship."</i>
	<i>"A mother's trustworthiness is of great importance to me, particularly when considering that almost 80% of remote communication is verbal, including no pictures or videos."</i>

Table 6.1b
The importance of trust in the **physician-carer** relationship

"I used to see a woman outside Attica (beyond the district of my professional practice); this woman suffered from chronic dysthymia. The situation was such that I would be there once a week, we had our session and I left. We did not have a relationship over the phone. We just had the face-to-face sessions.

Towards the end of our sessions she phoned me one evening, around ten, and told me, "I have just taken two boxes of pills, have made a suicide attempt and I am calling to say goodbye" and that "I have not informed anyone." She had never given any indication of suicidal thoughts – in essence, we exchanged around eighty phone calls. It was a four-hour process finishing around two-thirty in the morning. Having acquired her consent, I found her next of kin and informed him. It was with great difficulty that he was persuaded to go to the Health Centre. It was with even greater difficulty that she was persuaded to go to Athens voluntarily and into compulsory hospitalisation. I was trying to walk a fine line: on the one hand preserve trust and keep her close to me, yet at the same time, I was trying to delineate/define, in a manner of speaking, the self-evident fact that she was self-destructive. [...]

One could say we managed (she finally did no harm to herself), because a deep basis of trust had been built [...] however, after that, she disappeared [...]; in other words, we ran into each other in the street, she saw me and turned the other way.

A month and a half ago, this woman [3 years after the aforementioned crisis] came back and sought therapy. What was touching was that she just came out with it and told me "you were the only person I felt I could trust... the only person I felt I could rely on", whereas I thought she had given up because our trust had been broken and because that violent scene had taken place." (MHE2)

Excerpt 6.1

The value of trust in the **patient-MHE** relationship

To sum up, healthcare experts unanimously verified that trust was considered an integral part of such a power-asymmetric relationship, in accordance with the patient-physician and patient-to-MHE literature. Trust has been found to make a therapeutic relationship functional, while also activating the patient's self-disclosure, which is considered one of the keys to effective therapy. Surprisingly, in the light of my research, questions about how physicians experience their remote communication with their patients brought to light the aspect of *mutuality* and, hence, the concept of the *trustworthy patient/carer*. It should be kept in mind that the majority of patient-physician literature approaches to date highlight a trust-based relationship as if only the patient's trust mattered. It should also be noted that what we have had so far has been subtle, yet limited, indications that the patient-physician relationship is one based on *mutual* trust (Cook *et al.* 2004; Thorne and Robinson, 1988; Irwin *et al.*, 1989; Roter and Hall, 1992; Miller, 2007; Merrill *et al.*, 2002; Bültzingslöwen, 2005; Jain *et al.*, 2006; Thom *et al.*, 2011). Within the framework of the following paragraph, the limited knowledge we had so far with regard to the properties of the TP/C in terms of personal qualities and skills is expanded.

6.2 The *trustworthy patient (carer)*: physicians' vs MHEs' perceptions

The trustworthy patient as a physician's construct has been one of the key-themes of this PhD thesis, around which the whole research project was built. According to evidence provided in 6.2.1, the TP/C is a *skilful* individual with certain *personal qualities*. As highlighted in Chapter 7, the whole set of skills was found to contribute to the minimisation of risks (i.e. *misdiagnosis*, *personal and professional time violation*) that emerge during CMC sessions due to lack of accessibility to the patient's body. In sharp contrast to physicians, though MHEs highlighted that they experience their relationship with their patients as one based on mutual trust, they did not recognise the concept of the TP/C the phenomenon I define as the patient-MHE *trust paradox*.

6.2.1 The *trustworthy patient (carer)*: the physicians' perspective

One of the key-findings that highly affected the data-collection phase, even as early as the first two interviews, was the aspect of *mutuality* in the patient-physician relationship. The patient-physician literature perceives this relationship as asymmetric in terms of power and one in which only the patient's sense of trust matters. Since patients entrust the improvement of

their health, not to mention their lives, in the physicians' expertise, there is no doubt that the relationship is asymmetric. This is especially true in cases when the physician is the patient's personal choice (interpersonal trust) and not just a health expert assigned by a faceless health system. However, it was found that the patient-physician relationship is not a one-way trust-based relationship, but, rather, a bond founded on *mutual* rather than *one-way trust*, i.e. the *patient's trust*.

As my first interviewee mentioned:

"I will use data sent by a parent I trust in a completely differently way than data sent by someone who I know is in search of an easy solution."
(Paedia1)

In other words, Paedia1 implied that there are parents (carers) who are worthy of his trust and others who are not. Similar statements by my second interviewee (Paedia2) revealed that it was worth exploring whether the patient-physician relationship is one based on *mutual trust* instead of one-way trust (patient's trust).

"the paediatrician-to-parent relationship is reciprocal, isn't it [?]
Because they must trust me, and I should trust them, too!" (Paedia2)

Both statements from Paedia1 and Paedia2 were strong enough to prompt me, at that early stage, to probe into what physicians mean when they speak about a *trustworthy patient/carers*. In other words, the key-question that inevitably arose was:

"once you are talking about mutuality in your trust-based relationship with your patients, who is a trustworthy patient or what is the profile of the trustworthy patient?" (Researcher)

or, similarly,

"what is the profile of a trustworthy carer?" (Researcher)

in cases where communication with the patient him/herself is considered unfeasible.

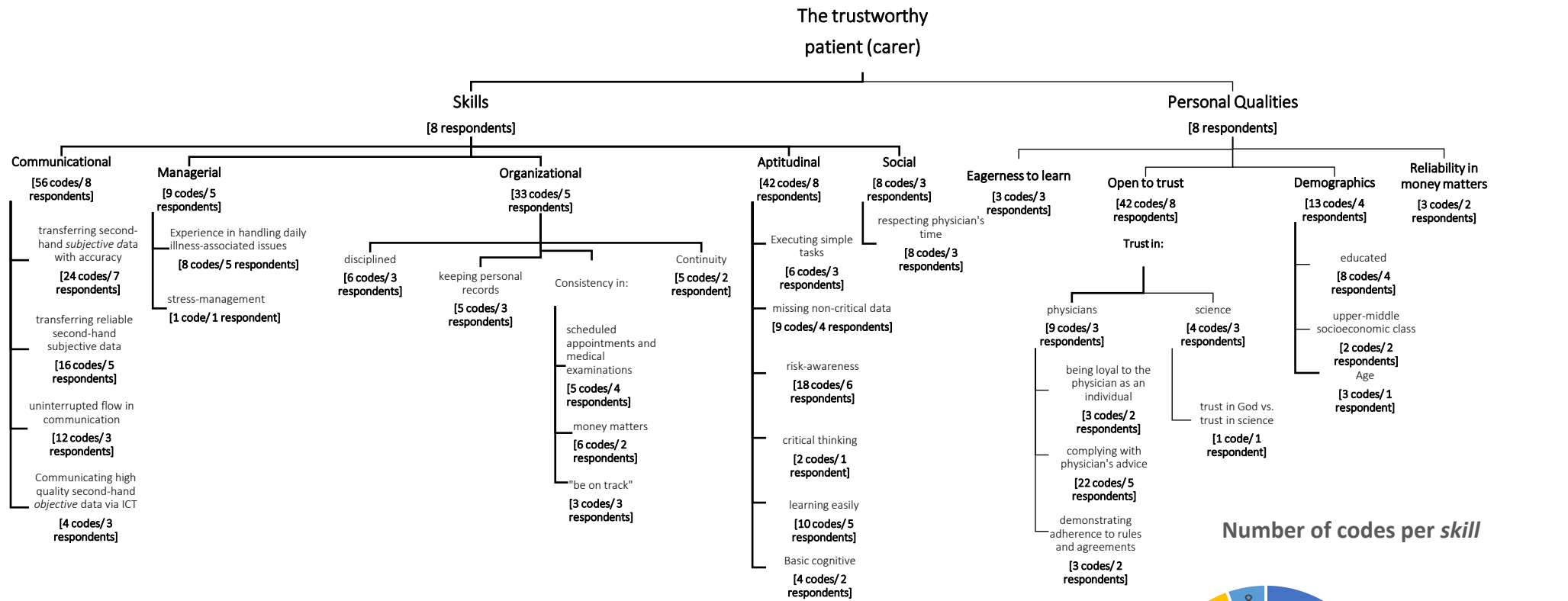
What is highlighted here is that, although researching into the profile of the *TP/C* seems to be irrelevant to the research aims of this thesis, key-aspects of his/her profile have been found to play a primary role in a physician's decision regarding how or even whether to respond to a patient's request for remote diagnosis or consultation.

Before moving on to the analysis of these specific aspects, it would be more effective to demonstrate the profile of the *TP/C* who seems to have certain *personal qualities* and *skills*. Tree-diagram 6.2.1 demonstrates how the codes built up the theme of the *TP/C* helping the chain of evidence.

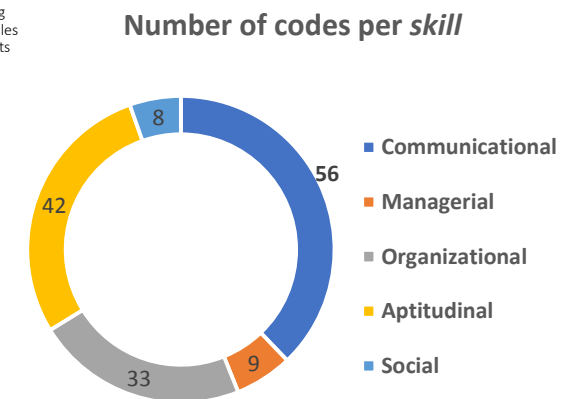
To be specific, the *trustworthy patient/carer (TP/C)* demonstrates some personal qualities, such as: (a) *eagerness to learn*; (b) *trust propensity* (*trust in physicians* and *trust in science*), and (c) *reliability concerning money matters*. Being *reliable with money matters* means that the *TP/C* pays on time and *does not look for the cheapest alternative solution*. As both Dent1 and Paedia1 emphatically stressed, patients' and carers' reliability with money matters does not only mean the individual is not grouped under the 'umbrella' of untrustworthiness, but, moreover, it affects the physician's decision as to whether or not they should open a remote channel of communication. Moreover, four physicians reported that the *TP/C* is found to be (d) *educated*. It was only Diab1 who challenged the association between the aspect of *trustworthiness* and college studies, while Phys1 associated education with a patient's ability to convey reliable and accurate data (i.e. effective communicational skills). Two physicians associated the *TP* with (e) *socioeconomic* and Paedia3 with (f) *age* criteria.

Although not all physicians mentioned the same personal qualities, *all* of them regarded the *TP/C* as a skilful individual who demonstrates *communicational*, and *aptitudinal* skills. Moreover, for most of the physicians the *TP* possesses *managerial*, *organisational* and *social skills*.

Trustworthy patients/carers appeared to be individuals with a set of (a) *communicational skills*, such as *transferring subjective second-hand data with accuracy* (either in written or verbal form), *transferring reliable subjective second-hand data*, uninterrupted flow in communication (*speaking skills*) and, finally, *communicating high-quality second-hand objective data via ICT*.



Tree-diagram 6.2.1
The profile of the **trustworthy patient** (physician's perspective)



As Diab1 clearly demonstrated,

“During my relationship with my patients, I document whether what they describe is what actually happened. That is a trustworthy patient.”
(Diab1)

Moreover, all physicians also stressed the importance of both patients’ and carers’ *ability to transfer reliable subjective second-hand data*, particularly when communicating remotely:

“I would prefer an SMS from a client who I know well, and I would know that out of the 5 things she has told me, all 5 are true, correct and reliable, and so; in my turn, I can tell her 2 things she must do, and we can move on and the issue can be resolved.” (ObGyn1)

It should be noted that *transferring reliable subjective second-hand data* is a skill that is also attributed to a *trustworthy carer* as well:

“It’s difficult to reach a conclusion over the telephone, especially about skin conditions like rashes. However, this has happened, as well. Not to be able to gather necessary and reliable information and to have to examine the kid [in the office].” (Paedia2)

Moreover, two physicians attributed *speaking skills* (coded as *uninterrupted flow in communication*) as a characteristic of the TP/C. As Paedia2 stressed:

“I remember a case when I was speaking on the phone with a parent about a skin rash of his son’s. And I remember me telling him that “I can’t make head or tail from what you are describing to me over the phone! I have to see the kid!” It is worth mentioning that he had an issue about the way he was using the word” (Paedia2)

Additionally, three out of the eight physicians interviewed referred to the ability of the TP/C to *communicate high-quality second-hand objective data* via ICT. As Paedia2 mentioned:

“The parent can’t convey the information I need for an accurate diagnosis using a photograph.” (Paedia2)

It should be underlined at this point that communicational skills, such as *transferring reliable subjective second-hand data* or *transferring subjective second-hand data accurately*, have been

assessed by physicians as key-communicational skills of the *TP/C* considered to play a fundamental role in the physician's decision as to whether to open a remote channel of communication with their patients or not (see Chapter 7).

Additionally, (b) *aptitudinal skills* encompass the ability to *execute simple tasks* with accuracy, *missing no-critical data* in the case of transferring symptoms, which is highly valued by all physicians, especially in the light of remote communication, *risk-awareness*, *critical thinking*, as well as the capacity to *learn easily*. Finally, the focused code of aptitudinal skills encompasses *basic cognitive* skills. With regard to the element of *risk-awareness*, Diab1 mentioned that:

“Look, the patient who is too laid-back is unreliable, in a way; in other words, they don't take what you say seriously. This is what laid-back patients do. They underestimate their condition, the problem.” (Diab1)

Similarly, Paedia1 stressed that:

“there are parents who are really laid back, to such an extent that you become anxious about them; for example, they bring the kid with a temperature of 39°C ... ”(Paedia1)

With regard to the skill of *missing no-critical data*, Paedia1, among others, such as Paedia2 and Phys1, stressed that:

“[t]hey are trustworthy in the sense that they will give you all the information. All of it, though. All of it.” (Paedia1)

With regard to a *TP/C's* aptitudinal skill to detect and report any critical data, Phys1 emphatically supported that:

“ ... it's common for what they describe (on the phone) not to be valid. For example, one case in point is of an elderly woman who told me “my ankles have swollen”. And I was wondering “how is it possible for this to happen to both ankles?” Later, when I had been to visit her, I saw that it wasn't both ankles that were swollen, but only one.” (Phys1)

Moreover, according to Paedia1, Paedia2 and Obgyn1, the *TP/C* also has (c) *social skills*, such as demonstrating respect for their physicians' personal and professional time by *calling for a*

specific purpose, i.e. for major rather than insignificant matters. As both paediatricians stressed:

“they (trustworthy parents) will only contact you and make a claim on your precious time when there is good reason.” (Paedia1)

“A baby with a high temperature will have some difficulty, or s/he will vomit, which is an urgent condition. And it is normal for you to be disturbed [for advice] once or twice.” (Paedia2)

Trustworthy patients are also known for being able to (d) efficiently *manage* either easy or complex tasks, associated with their therapy and health status. According to Diab1, Phys1 and Ophthalm1, there are groups of diseases, such as diabetes and therapies (i.e. multi-medication), which are very demanding in terms of *managements skills*. So much so, that patients are not always able to follow instructions. For example, Ophthalm1 believes that a patient’s skills to manage such difficult tasks is decisive in making them *trustworthy* or *untrustworthy* as patients.

“One of a physician’s basic task is to be aware of how much treatment guidance a patient is capable of complying with. It is common sense among ophthalmologists that several eye-drops at different times and dosages within a single day will drive the patient crazy to such an extent that –at the end of the day- they will not be able to comply.” (Ophthalm1)

Both paediatricians stressed that those parents who demonstrated efficient management skills concerning tasks associated with their child’s illness and ranging from easy to complicate, were also regarded as *trustworthy*.

One of the most valuable management skills that a TP/C possesses is managing stress efficiently (coded as *stress-management skills*). It is underlined that the ability of a patient to efficiently manage their stress, in the light of an unexpected event, is highly valued by physicians.

As Paedia2 stressed:

“(Trustworthy parents) are those who usually don’t become anxious over the smallest detail, something which you observe over the course of managing the case.” (Paedia2)

Besides their social and managerial skills, *TP/Cs* also stand out for their (e) *organisational skills*, namely, *discipline*, *keeping personal records*, as well as *being consistent with scheduled appointments* for medical examinations. As Paedia1 mentioned:

“the most trustworthy (parents) are those who are organised”
(Paedia1)

ObGyn1 not only verifies the patient-physician relationship as one based on mutual trust, but also makes a clear statement about how *keeping scheduled appointments* is vital for sustaining their relationship:

“[...] If women don't visit us to have specific tests at certain time intervals during their pregnancy (i.e. blood tests or ultrasound examinations) then the physician’s trust in the patient is gone, since the explanation of how important it is for these to be performed at specific points in time during pregnancy has already been given. When they don't follow such guidelines, then trust is certainly pretty shaken.”
(ObGyn1)

Trustworthy patients and carers not only demonstrate *discipline* when following a physician’s instructions, but, furthermore, they either keep a personal diary of their own observations and questions, as patients (or carers), or they keep notes while they are at the physicians’ office, which often means fewer unnecessary phone calls.

“[referring to a trustworthy patient] he came along to my office with a list of questions about his therapy, the meds he was taking and their side-effects” (Phys1)

Similar skills were reported by paediatricians with regard to *trustworthy parents* in their role as informal carers. As Paedia1 stressed:

“[Trustworthy parents] will ask the necessary questions before they leave their scheduled appointment so that they may have all the information they need and there will be no silly phone calls about broccoli in the kid’s soup.” (Paedia1)

Paedia1's view that

“trustworthy for me is one who honours the relationship with continuity and conscientiousness” (Paedia1)

is also shared by the rest of the interviewees.

Under the code *continuity* there have been grouped patients and carers who (a) do not change physicians very often; (b) who are regular in their visits, while they also (c) inform their physicians when they have visited another healthcare professional, for whatever reason, since their last visit.

“If you don't have continuity in keeping the history of the patient, you cannot really assess the situation satisfactorily and you may miss important points.” (Paedia1)

It has been made clear so far that a *TP/C* is a skilful individual characterised by a set of personal qualities. As will be exhaustively discussed in Chapter 7, it was observed that physicians not only hesitate to implement any medical act remotely, but they even block remote communication with individuals who appear to be *untrustworthy*, particularly in terms of *communicational skills*. Physicians' emphasis on patients' communicational skills could probably explain why the incidences of codes regarding communication skills were more prevalent in their interviews.

6.2.2 The *trustworthy patient*: the MHEs' perspective

Having collected and analysed the data offered by the group of physicians, I started collecting and analysing data acquired by the group of MHEs. Similarly to physicians' data, I examined the MHEs' experience through asking questions about the importance of trust. However, in this round of interviews I started collecting data in the perspective of specific topics (*mutuality*, *trustworthiness*, *MHE's knowledge of patient*) and codes (*communicational skills*) that had hitherto emerged and been shaped. It is worth highlighting that the aspect of *mutuality* in the patient-physician relationship, and, hence, the concept of the *TP/C* was found to play a critical role in physicians' decisions as to whether they should open a remote channel of communication with their patients or not (see Chapter 7). Surprisingly, though, all MHEs

admitted that they invest in and, therefore, risk –i.e. the core of trust- time, money, emotions and expectations every time they engage in a therapeutic relationship; they barely recognised the concept of the *TP/C per se*.

“Indeed, at a practical level, patients who hide things from us are untrustworthy. At a deeper level, I am not quite sure if I would characterise them like that [...] according to our therapeutic contract, I will not call someone untrustworthy even if they are.” (MHE2)

As previously mentioned, MHEs support that trust lies at the core of the patient-MHE relationship. All MHEs underlined that it is of great importance that their patients see them as trustworthy; this confirms Roger ‘s (2012) thesis that trust is an integral part of the patient-MHE relationship. Nevertheless, physicians support that trust-maintenance demands active participation by both parties. This offers subtle indications that the aspect of *mutuality* includes the patient-MHE trust-based relationship, too (Table 6.2.2a).

To be specific, in the later stages of data-collection, I went on making use of the codes constructing the theme of the *TP/C* in order to enrich them until *theoretical saturation* had been achieved. I began by offering a briefing about the physicians’ perspective on the aspect of *mutuality* in their relationship with their patients, as well as insights on the *TP/C*. Initially, individual quotations mentioned below seemed to verify that the *TP/C* is a concept that exists for both physicians and MHEs. For instance, DramaTh1 demonstrated that there are patients whom he trusts and others he does not:

“Provided we trust one another. OK?” (DramaTh1),

while both MHE6 and Psych1 mentioned that patients may potentially risk that trust-based relationship:

“Patients contribute in their own way to that BIDIRECTIONAL relationship and, therefore, they may potentially damage it.” (Psych1)

“the therapeutic relationship includes risks for both parties [...]” (MHE6)

Similarly, MHE1 concluded that maintaining trust in the patient-MHE relationship requires effort by both parties. The implication was that patients may potentially damage this trust-based relationship.

“The candle light (representing trust for MHE1) cannot be looked after only by one person; that's certain!” (MHE1)

Though individual statements offered by DramaTh1, MHE1, MHE6 and Psych2 initially revealed that the TP/C is a concept that exists for both physicians and MHEs, the latter barely recognised its existence (Table 6.2.2b). As the screenshot 6.2.2 taken from the NVivo (Version 12) demonstrates, although 3 MHEs mentioned properties that could be attributed to an *untrustworthy patient* (*protocol violation, disrespecting confidentiality issues, inconsistency in money matters*), all MHEs emphatically showed lack of awareness about such a type of patient.

▼ ● Untrustworthy	0	0
● Confidentiality issues (being recorded)	2	2
● Demonstrating lack of commitment to therapy	3	8
● Inconsistency in money matters	3	4
● Inconsistency in scheduled appointments	3	5

Screenshot 6.2.2

Additionally, eighteen initial codes provided by three MHEs, revealed that key-communication skill, such as accurate transfer of data that matter for physicians, are not an issue at all for MHEs.

Trust in the therapist-to-patient relationship takes two	
DramaTh1	<p>If trust was a painting, it would depict a container, imagine a deep bowl, sturdy, truly solid, but wooden. Not made of metal, but of wood; in the sense that it is a warm thing. There is no warmth in metal, right? This is where the bowl is held by both hands of the one person, and the hands of the other hold the hands of the former. Preferably, the person who holds the bowl and the hands is the therapist. He controls/holds things/himself/herself together. Right? That's how they are together.</p> <p>"Provided we trust one another. OK?"</p>
MHE1	<p>If trust was an object, it would be a lit candle, which needs care so that it does not go out. It might flicker with the draft, but we are there to ensure and to set up the framework protecting it and the candle does not go out.</p> <p>If trust was a painting it would depict a man (the patient) on a boat trying to reach the shore, and a second individual on the shore (the therapist) who is trying to pull the boat towards the shore ... so, they are both trying so that the boat reaches the shore ...</p>
MHE2	<p>If trust was a painting, it would depict .. two people (the therapist and the patient) who are pushing a boat into the sea so that it may travel; in other words, they activate it to depart for a safe trip. The boat symbolises the relationship of trust; it knows that it can cross the sea even in high wind without trouble, but that it needs both of them to be pushing.</p>
MHE6	<p>"If my trust-based relationship was a painting it would depict a boat representing the therapist, a paddler representing the client, and a sea with lots of lanes representing the constraints of that relationship. A trip with lots of ports representing any experiences without a specific destination"</p>
Psych1	<p>No relationship can be one-way</p> <p>The doctor (psychiatrist) invests in the relationship. If they do not invest in the relationship, I think that the relationship will not be right and this is something the patient feels; therapy won't work.</p>

Table 6.2.2a
The aspect of mutuality in the patient-MHE trust-based relationship

In fact, the MHEs' response to the issue of a *TP/C*'s communicational skill was that providing distorted data, either intentionally (i.e. lying) or unintentionally (i.e. the concept of one's *personal myth*), does not characterise a patient as *not trustworthy*. Although *self-disclosure* on behalf of the patient is considered as a prerequisite condition for effective therapy, all MHEs underlined that patients often hesitate to share their issues, emotions, experiences or concerns, even with psychiatrists, because of not yet being ready to do so. They also underlined that patients who distort events unintentionally (*personal myth*) should not be considered untrustworthy, since this is what they actually perceive as real. In other words, the patient's intention is not to lie and, hence, undermine the bond of trust with their MHE. As DramaTh2 mentioned, lies are valuable information for further analysis and assessment rather than disoriented bits of information that undermine trust.

"Lies are useful data for us (MHEs)" (DramaTh2)

Overall, only nineteen initial codes identified within the MHEs' transcripts could be associated with patient's trustworthiness. It is highlighted that this limited volume of data was not associated with any of the *TP/C*'s skills but with issues regarding integrity (see Table 6.2.2). It is also worth mentioning that even that shallow cluster of data collected after my persistent question "*What if there was an untrustworthy patient? How would he/she be?*". The significant divergence between the initial codes collected by physicians and the ones collected by MHEs with regard to the *TP/C* i.e. 216 vs. 19, verifies that the *TP/C* as a social construct exists only for physicians.

To sum up, on the one hand MHEs implied that their relationship with their patients was based on mutual trust, while, on the other hand, they did not demonstrate that they were familiar with the concept of the *TP/C* (i.e, the patient-MHEs *trust paradox*).

Inevitably, the question emerging at this point is "*how is it possible to speak of a mutual trust-based relationship without the participation of two trustworthy parties?*" This paradox could possibly be attributed to *power asymmetry* issues. As Dramath1, MHE6 and Psych1 mentioned:

"It is the patient who cares the most about the aspect of trust. I care more about how much my way of working could be helpful." (DramaTh1)

“Engaging in a therapeutic relationship includes risks for both parties, but mostly for the patient” (MHE6)

“yes ... the patient-therapist trust-based relationship is not symmetrical in the sense that the therapist holds a more powerful position” (Psych1)

Therefore, I attribute the paradox of having a mutual trust-based relationship in the absence of two trustworthy parties to the significant power asymmetry inherent in the relationship. In other words, MHEs experience the relationship as asymmetrical in terms of power, to the extent that they hesitate to claim it involves two parties supposed to be equally trustworthy. Finally, only fourteen initial codes were identified in the MHEs’ transcripts, compared to the total number of two-hundred and thirteen codes that emerged from physicians’ transcripts. That limited number of codes which was exclusively associated with integrity issues rather than skills, is one of the focal points of this PhD thesis. It should be reminded that skills are considered by traditional trust literature as an integral part of trust.

6.3 The *medical data* theme

Within the framework of the current PhD thesis, patients’ (carers’) communication skills have been found to play a key-role for physicians’ decision on whether or not to open a channel of remote communication with their patients in the light of their request for remote assistance, guidance or, even, diagnosis. As it has already been demonstrated and analysed, the focused code of communication skills refers to the ability of a patient to communicate with accuracy two broad categories of data, namely, *subjective* and *objective data* or even a mixture of the two. The following sub-section has been designed not only in order to define the terms *subjective* and *objective 2nd-hand data*, but, mostly, in order to demonstrate the extended theme of *medical data*, i.e. the data that attract physicians’ and MHEs’ interest both in face-to-face and CMC sessions. That broad cluster of data attracting healthcare experts’ interest has been coded and classified and this analytical work helped identify the significant differences that exist between the type of data that attract physicians’ and MHEs’ attention. In brief, physicians were found to be keen on (a) *on-line data*, (b) *third-party data*, (c) *first-hand*

<i>What trustworthy patient?</i>	
DramaTh1	<i>"But the lack of honesty, I would consider it part of the defence mechanism complex vis-à-vis the process."</i>
DramaTh2	<i>"I am not interested in this (trustworthiness). I have worked with people that one knows they are lying to you. I am not interested in that. The point is for them to tell you their own truth. They may need to experience through you, during the session what good is. It does not matter."</i>
MHE1	N/A
MHE2	<i>"in the context of psychotherapy, what the therapist has to do/to deal with is one's personal myth. That's where you cannot characterise the other person as trustworthy or untrustworthy, on the basis of what is spoken/said and not spoken/said or to expect trustworthiness"</i>
MHE3	<i>"there is no trustworthy and untrustworthy patient. There is no such thing for us. What matters is the truth each one is carrying within. This is what they perceive and this is what they bring."</i>
MHE6	<i>"The concept of the trustworthy patient does not exist to me because I do not care about a patient 's trustworthiness"</i>
Psych1	<i>"the notion of the trustworthy patient does not exist to me [...] "</i>
Psych2	<i>"In other words, when I realise that a patient exaggerates* they do not lose their trustworthiness, I simply translate what they are saying to my own understanding/comprehension."</i>

Table 6.2.2b
"What trustworthy patient?"

data and, finally, on (d) both *objective* and *subjective second-hand data* (Tree-diagram 6.3.1). At the other extreme, MHEs seemed to be very keen on (a) *verbal data* that is traditionally considered as the main pool of data by all specialties and schools of thought in mental-health sciences, and (b) *non-verbal data*, which, however, bear no resemblance to the data attracting physicians' attention. It should be reminded that, in accordance to the classical CMC literature not all data are considered as equally rich, while not all mediums (ICT) can provide all kinds of data.

6.3.1 *Medical data taxonomy: the physicians' perspective*

The term *online data* includes data directly sent to physicians via mobile or wearable devices (either indoor or outdoor ones) without the patient's or a third party's intervention. *Online data* include types of data such as oxygen saturation levels, cardiac pulse rates, blood pressure readings, miles run, body temperature, etc.

"I used to know a colleague in New York, a resident, whose son suffered from diabetes. My colleague used to monitor his son's blood sugar levels from New York, while his son was playing football in San Francisco." (Diab1)

At first glance, *online data* appear to have the following properties: (a) *remotely accessible*, (b) *real-time*, (c) *storable*, and (d) *undistorted*, given that there is no user-intervention in the data-transferring process at all (Table 6.3.1a).

The term *third-party data* includes data directly sent to physicians by other healthcare professionals without any intervention on the part of the patient. *Third-party data* include medical reports, medical examination results or data sent in video or picture format. Additionally, two types of *third-party data* emerged during the data-collection stage, namely, (a) *standardised data* (official medical exam reports, microbiology test result reports, x-rays, axial tomography videos and images, etc.), and (b) *non-standardised data*, such as snapshots of symptoms or original medical reports created and shared through healthcare professionals' personal ICT (Table 6.3.1a).

The second most dominant category of data that emerged was *first-hand data* (Table 6.3.1a), which include data collected either through hands-on techniques or through making use of medical equipment at the physician's office. In other words, *first-hand data* are collected by physicians themselves without any other patient's or colleague's intervention, using their own senses (i.e., smell, touch, watching or listening) or technological equipment (i.e., ultrasound). *First-hand data* include types of data which are either (a) *inaccessible in remote communication* or (b) *invisible to patients* (coded as *stealth to patients*), while they are considered as (c) *richer* than data sent by patients and (d) *objective*, since there is no intervention on the part of the patient.

Overall, though no emphasis is placed on the properties of on-line, third-party and first-hand data paid during the data-collection phase, they are all considered as objective, reliable and undistorted *a priori*. That is because all these types of clusters of medical data are produced either through the physicians' sensory work or through mechanical or digital medicine.

However, the group of data that prevailed during the data-collection stage, and which was found to finally play a critical role, were *second-hand data*, which are defined as data directly sent by patients or carers to physicians without any other healthcare experts' intervention. *Second-hand data* include any raw information provided by patients to physicians, either verbally or in a written format, such as health indices (i.e., oxygen saturation levels, body temperature, miles run, blood pressure indices, blood sugar levels, etc.), symptoms (i.e., dermatological indications), events (i.e., description of an accident) or experiences (i.e., pain-levels). *Second-hand data* also include non-verbal data, such as photos or video recordings sent by patients and carers. Three sub-groups of *second-hand data* were identified: (a) *objective*, (b) *subjective* and (c) *mixed*.

Objective second-hand data are collected and sent by patients and carers themselves and are not susceptible to the sender's subjectivity (photos, videos, etc.).

"pictures offer a much more objective view of the case, because you get an actual picture of the symptom itself" (Diab1)

	Data	Definition	Examples		Properties	Quotes
1	On-Line Data	The term <i>on-line data</i> includes data directly sent to doctors by mobile or wearable devices (either indoor or outdoor) without any patient's or third party's intervention.	oxygen saturation levels, cardiac pulse rates, blood pressure values, miles run etc.	1.1	<i>accessible in remote</i>	"the ideal scenario would be receiving data on your PC directly from the mobile medical device without any intermediary's intervention" (Diab1)
				1.2	<i>storable</i>	
				1.3	<i>undistorted</i>	
				1.4	<i>real-time</i>	"I used to know a colleague -a New York resident- whose son was suffering from diabetes. My colleague used to monitor his son's blood sugar levels from New York while his son was playing football in San Francisco." (Diab1)
2	Third-party data	The term <i>third-party data</i> includes data directly sent to doctors by other healthcare professionals without any intervention on the part of the patient.	medical reports, medical examination results, data sent in video or picture format.	2.1	<i>reliable</i>	"It is common for me to receive photos from colleagues like midwives who use to send me snapshots from cardiocographies through smart phone apps" (ObGyn1)
				2.2	<i>objective</i>	"It is common practice for me receiving medical exam reports in a digital format from colleagues -such as microbiologists- and saving them in my patient's PC folder [...] in that way, I manage to have instant and quick access to my patients' test results." (Pedia1)
				2.3	<i>accessible in remote (transferable)</i>	"It is common practice in the US for physicians or experts in diabetes to send pictures from the depth of the human eye to ophthalmologists for diagnosis" (Ophthalm1)
3	First-hand data	First-hand data include data collected by doctors themselves either through clinical examination or making use of medical IT equipment at doctor's premises. In other words, first-hand data are collected by doctors themselves without any other patient's or even colleague's intervention either making use of their own senses (i.e. smelling, touching, watching or listening) or utilising technological equipment on their own (i.e. ultrasound).	Clinical examination data	3.1	<i>Objective</i>	"(remote communication) eradicates the risk of misdiagnosis or miscalculation due to the subjective observations of a patient who is not to be considered trustworthy; so, I prefer to use my own criteria, which are objective rather than subjective" (ObGyn1)
				3.2	<i>inaccessible in remote (non-transferable)</i>	"In dentistry, it's not only the picture that matters ... it is also patient's temperature or mouth's smell that affects decision-making ..." (Dent1)
			Data collected by doctors themselves through professional medical equipment (ultrasounds etc.)	3.3	<i>stealth to patients</i>	"[...] during the clinical examination you finally see that your patient is suffering from reduced eye-vision capacity, or that he had gone through a heart attack or a light stroke and he was not aware of that (!) because it was not painful" (Diab1)
				3.4	<i>rich</i>	"having your patient in front of you is quite different from having a photo attached in descriptions of the symptom because in the clinical examination you have the patient himself who is a much more complex object and subject. I mean that in clinical examination you can see various things ..." (Pedia1)

Table 6.3.1a
Online, third parties' and first-hand data

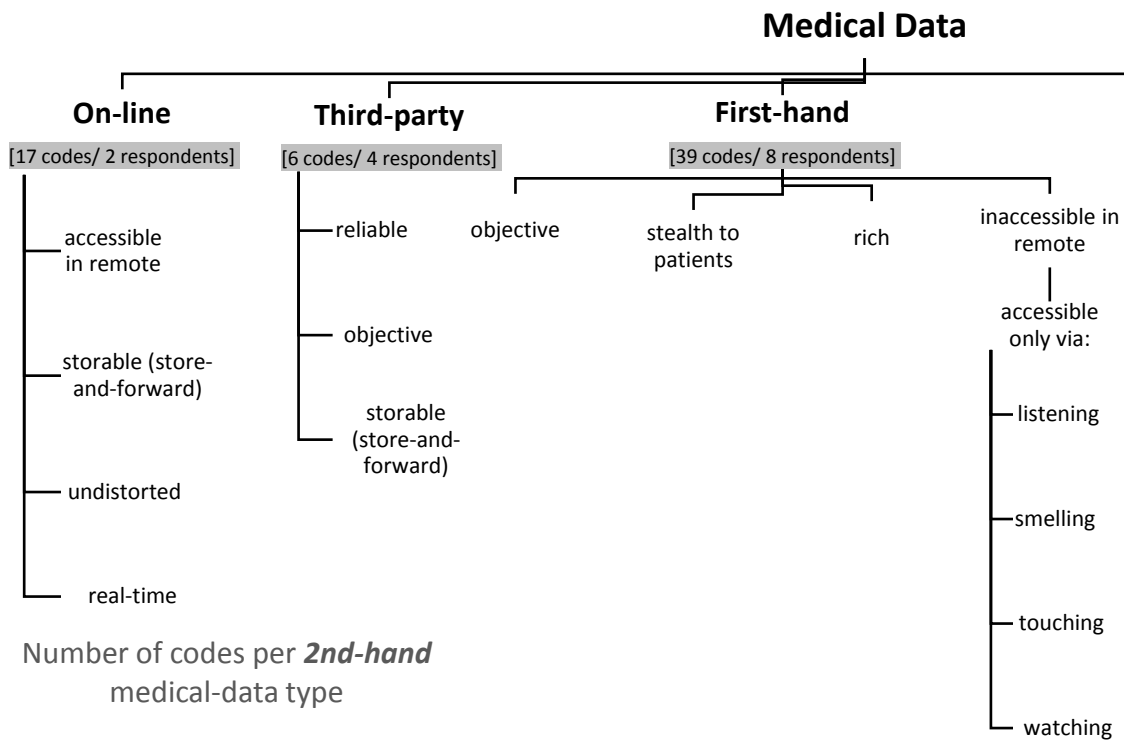
In brief, *objective second-hand data* are (a) *transferable*, (b) *storable*, (c) *editable* and, hence, offer the option of being saved and shared for further analysis; they constitute data that did not emerge during the clinical examination session. Both Pedia1 and Phys1 stressed the opportunities that video data offer, even compared to clinical examination. Both mentioned that videos offer the opportunity to capture data which are neither easy for non-experts to describe nor detectable during clinical examination.

“I recently had a case of a mum who was trying to describe some unusual body reactions of her young child because she was afraid that her son was having seizures. So, she sent a video that was very helpful in excluding seizures as a diagnosis and, thus, eliminate some possible causes. It helped me figure out whether it was something really urgent that might have needed an encephalogram or an immediate visit to a neurologist.” (Phys1)

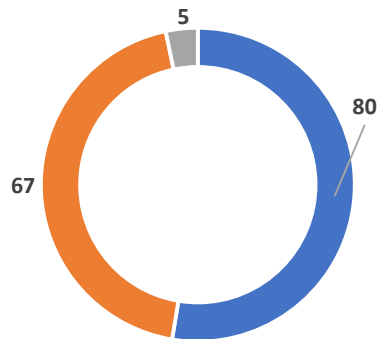
Subjective second-hand data include any kind of data not remotely accessible, whether measurable (body temperature, blood pressure, etc.) or not (dermatological symptoms, pain-levels, etc.). In other words, in a remote communication setting, the healthcare expert solely relies on the patient’s (carer’s) observations and, therefore, aptitude skills before making any decision. *Subjective second-hand data* include any experience or description in verbal or written form, such as SMSs, e-mail messages, personal diaries and reports.

Subjective second-hand data are considered (a) as *equivocal* including a great level of (b) *risk*, since they depend on the patient’s or carer’s understanding or reality perceptions. Though *subjective second-hand data* are (c) remotely *inaccessible*, they are (d) *transferrable*.

Finally, the term *mixed second hand data* refers to a mixture of *subjective* (verbal or written) and *objective second-hand data* (such as photos, videos, etc.) sent by patients or carers to physicians for assessment. For example, a photo sent to the physician as an MMS accompanied by extra information about the conditions in which the accident happened, is considered a set of mixed-data.



Number of codes per *2nd-hand* medical-data type



■ Objective ■ Subjective ■ Mixed

Tree-diagram6.3.1
Medical data taxonomy (physicians' perspective)

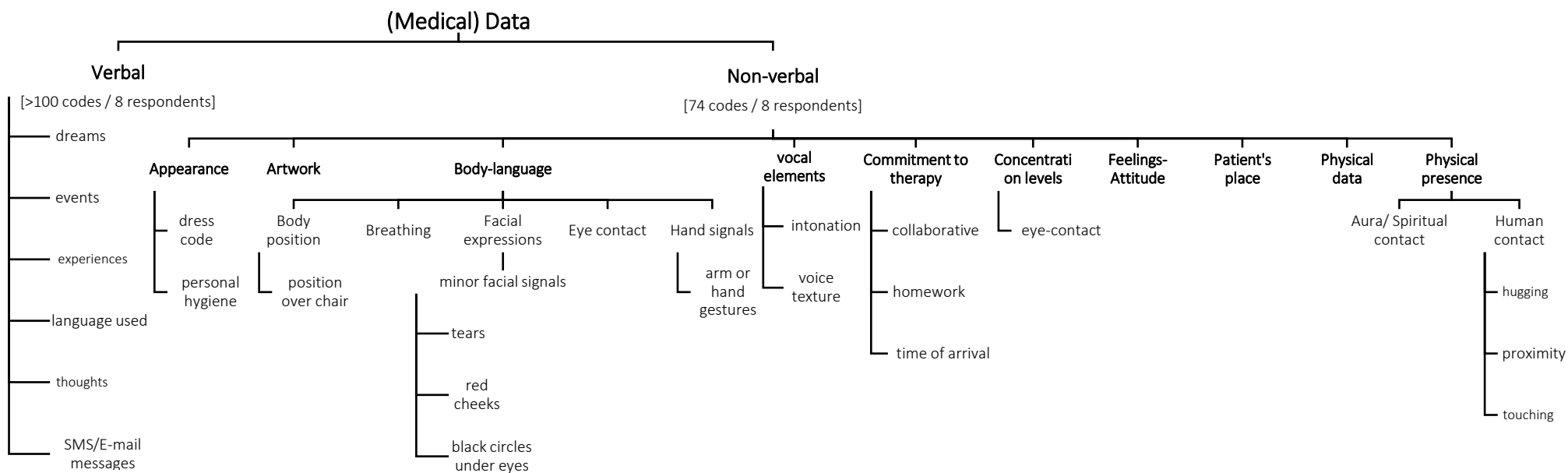
“if I receive a message attached to a photo telling me “this is where the bee bit my child, who scratched it and now it is infected”, it is something I can easily work with, especially if it is an HD photo, and diagnose a dermatological infection on a bee sting.” (Pedia1)

To sum up, physicians’ concerns regard the quality of *subjective second-hand data*, since they are not directly accessible to physicians who, thus, rely on a patient’s trustworthiness in terms of communication skills to make their decisions. As demonstrated in the following paragraph, MHEs do not share physicians’ concerns, since all relevant data they seek are accessible to them during VTS, while they miss few data from the parts of the body not visible during the session.

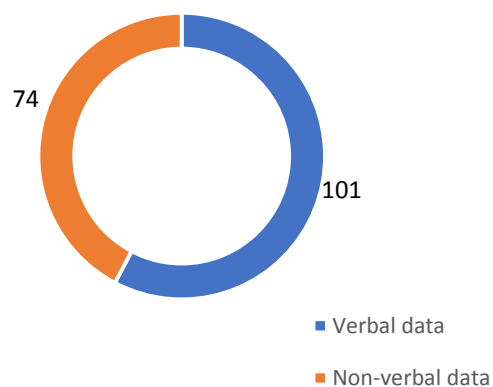
Finally, Tree-diagram 6.3.1 demonstrates how the codes built up the theme of the *medical data* helping the chain of evidence.

6.3.2 Medical data taxonomy: MHEs’ perspective

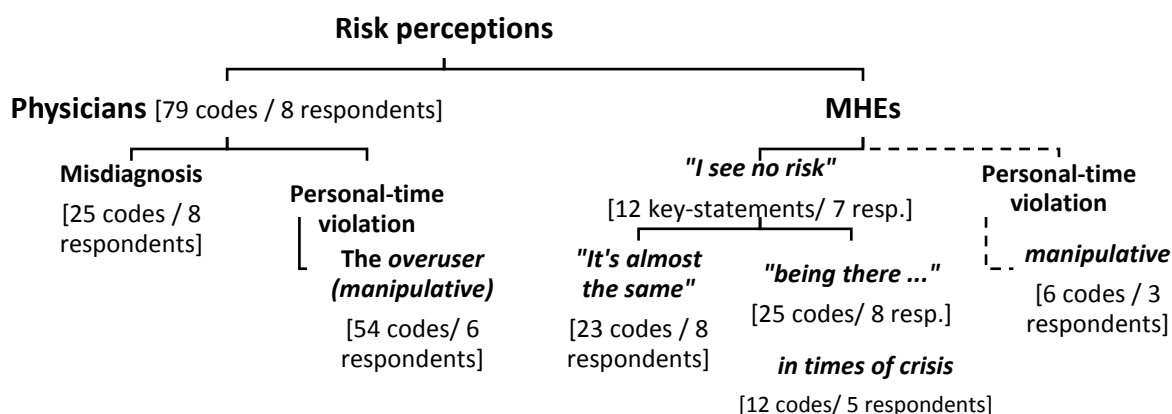
According to the American Psychological Association (APA), psychotherapy -often referred to as talk therapy- is based on dialogue. That is why MHEs interviewed were found to have a special interest in *verbal data*. *Verbal data* include any subjective information transferred by the patient to the MHE through speech. These include actual events, dreams, inner thoughts or experiences, whether intentionally distorted (lying) or unintentionally distorted, e.g., illusions of grandeur. Moreover, based on data collected, MHEs show a special interest in *non-verbal data* too, such as (a) *body signals* coming either from the upper or lower part of the patient’s body; (b) *facial expressions*, or (c) *feelings* transferrable verbally or non-verbally through facial expressions or body language. Additional *non-verbal data*, such as *levels of concentration* during therapy sessions or *commitment to therapy*, are also of special interest to MHEs. Tree-diagram 6.3.2 demonstrates how codes built up the theme of the TP/C helping the chain of evidence.



**Number of codes per (medical) data
(MHEs' perspective)**



Tree-diagram 6.3.2
(Medical) Data taxonomy (MHEs' perspective)



Tree-diagram 6.4

Healthcare experts' risk perceptions

It should be noted that groups of specialised MHEs, such as play-therapists⁹ or drama-therapists,¹⁰ would focus on data presented in the form of artwork, such as sculpture using various materials, painting or any form of artwork, e.g., body movement, singing or even role-playing.

6.4 Risk perceptions: physicians' vs MHEs'

One of the key-observations made within the framework of the current thesis was that physicians and MHEs do not share the same *risk perceptions* associated with CMC modes of communication with their patients. The following paragraphs present the focused code of *risk perception* per group of healthcare experts.

In particular, all physicians expressed concerns about the quality of their decisions made based on second-hand data provided by their patients in remote via ICT. The risk that prevailed in

⁹ According to the Play Therapy United Kingdom (2017: online) 'Play Therapy uses a variety of play and creative arts techniques to alleviate chronic, mild and moderate psychological and emotional conditions in children that are causing behavioural problems and/or are preventing children from realising their potential.

¹⁰ According to the British Association of Dramatherapists (2017: online) "Dramatherapy is a form of psychological therapy in which all of the performance arts are utilised within the therapeutic relationship. Dramatherapists are both artists and clinicians and draw on their trainings in theatre/drama and therapy to create methods to engage clients in effecting psychological, emotional and social changes. The therapy gives equal validity to body and mind within the dramatic context; stories, myths, playtexts, puppetry, masks and improvisation are examples of the range of artistic interventions a dramatherapist may employ."

interviews with the group of healthcare experts and was associated with any remote mode of communication via ICT was the one of *misdiagnosis*. As most of the interviewees mentioned, it is common sense that risk of misdiagnosis carries *legal risks* (i.e., lawsuits), *financial risks* (i.e., financial penalties) and, consequently, the risk of *defamation (reputational risks)*. In more detail, 35 events of patient-physician CMC identified where the physician's major concern was to minimise or even eliminate the risk of *misdiagnosis*.

The second risk identified, however, not shared by all physicians, was the sense of both their personal and professional-time being violated due to the overwhelming number of incoming phone calls (or texts) from their patients even at inappropriate hours regarding non-emergency matters. This class of patients was coded as *overusers* and it is further described and analysed in Chapter 7.

On the contrary, the group of MHEs not only made no reference to the risk of *misdiagnosis*, but, additionally, they stated that they experience CMC as *risk-free* regardless of whether they are regular video conference sessions or mini crisis interventions via telephone during out-of-office-hours. Specifically, with regard to the option of the VTS, which is their major tool for substituting face-to-face sessions, they mentioned that

"I don't think Skype sessions bear any risk in the literal sense of the word 'risk', but, rather, with regards to a deficit in human contact."
(DramaTh1)

"I don't see Skype sessions as risky; the only risk is when you cannot help someone sufficiently." (DramaTh2)

"I haven't perceived VTS as a threat and this is why I told you that I experience it as another kind of relationship." (MHE2)

"Where is the danger that you see in VTS? Because I see none." (MHE3)

"I have not felt that I am in any danger myself, let's say, or that the patient is in any danger, either." (Psych1)

"I can't think of anything that might threaten my trust relationship with my patient when communicating from a distance" (Psych1)

"I see no danger" (Psych2)

At this point it is worth noting that I would consider it an unexpected finding that MHEs perceive remote modes of therapy sessions via ICT as *risk-free*, given that four out of the eight MHEs interviewed mentioned that they would feel annoyed in the light of incoming phone-calls or texts from their patients for non-emergency matters.

Surprisingly, MHEs not only experience remote communication with their patients as risk-free, but also as *almost the same*, if not equivalent, to face-to-face sessions. *It is almost the same* or subtle variations of that initial code, were some of the phrases that frequently appeared during the course of my interviews with the group of MHEs. Initial codes such as *I see no difference*, *it feels the same* or *I felt no difference* emerged when I asked MHEs to compare and contrast how they experienced regular face-to-face sessions with VTS. It should be noted that the initial codes mentioned above were finally merged under the code named *It's almost the same* (see Table 6.4).

It is worth commenting that the absence of *risk*, as part of the MHEs' experience of their CMC with their patients, provides adequate explanations about the *trust paradox* identified within the current chapter. In brief, the existence of risks (i.e. misdiagnosis, personal time-violation) as part of the physicians' CMC experience with their patients, verifies the 'existence' of the TP/C, at least as a social construct. Respectively, the fact that the MHEs experience CMC with their patients as *risk-free* verifies that there is actually no such thing in their professional daily reality a TP/C.

Finally, as demonstrated in the following sub-section (6.5), MHE do not see any risks in remote communication, they see opportunities. To be specific, the accessibility provided by contemporary ICTs not only does not threat the trust-based relationship between MHEs and their patients, but it has the potential of nurturing. In brief, all MHEs unanimously supported that *being accessible to their patients* via ICT is an alternative way of "*being there*" for them, which is the essence of trust in the patient-physician relationship.¹¹

¹¹It is underlined that the findings demonstrated henceforward, regard data exclusively collected from mental-health experts. It was not possible to implement a new round of follow-up interviews with the group of physicians due to time-constraints. Although the findings demonstrated here do not add new knowledge to the existing literature, they do verify what is already known by the limited literature review on the positive effect of the accessibility offered by any ICT, regardless of its synchronous or asynchronous nature.

6.5 “Being there, being present, being supportive”

“As a MHE, I believe that being accessible (via SMS or phone calls) has a positive impact on my relationship with my patients.” (DramaTh1)

DramaTh1’s statement mentioned above introduced the element of *accessibility* to my research scope. This directed me to revisit the data I had so far collected and to examine them through the lens of accessibility. Earlier she had mentioned that

“being there, being supportive, being present are some of the strategies I use consciously and intentionally” (DramaTh1)

in order to sustain the trust-based relationship with her patients. According to DramaTh1, *being there, being present, being supportive* is a quality that demonstrates to the patient that the MHE cares. It should be reminded that the item of *benevolence*, which I interpret as a form of care, is considered as an integral component of trust, along with one’s ability and goodwill in classical trust literature. This view is also held by DramaTh1 who supported that:

“If the patient-to-MHE relationship was a painting, trust would be the canvas and **care** would be the drawing [...] my experience has shown that trust is built from a combination of things. **Care** and **support** from the MHE come first.” (DramaTh1)

While revisiting data collected from MHEs through the lens of accessibility, I found that the term *being there, being present* or subtle variations thereof, such as, *not feeling alone* or *being close to him/her*, had been repeatedly used by all MHEs, offering indications of theoretical plausibility.

<p>"I have the same feeling as when I am working at the office. VTS makes no difference to me." (MHE3)</p> <p>"We met every fortnight [via Skype] and we worked very well – it worked almost like an individual session" (MHE6)</p> <p>"(As a client) I felt no difference whatsoever" (MHE6)</p> <p>"I also don't think that distance plays any role or, rather, it does not play such an important role as we tend to think it does. In other words, I don't believe it has anything to do with seeing them at the office or seeing them via Skype." (Psych1)</p> <p>"A VTS is just like a session at the office." (Psych1)</p> <p>"But I see no difference in seeing someone on Skype from having them here, in my office." (Psych2)</p> <p>"I see no difference in sessions on Skype. In other words, if we weren't now talking in the office, how would that differ from talking on Skype?" (Psych2)</p> <p>"Differences between Skype and face-to-face sessions are not such that one might say "it is the end of the world!". In other words, it is not like I'll say "No, I'm never going to have a Skype session again". (DramaTh1)</p> <p>"This is why I am not of the opinion that a video call session is in some way so inferior as to become prohibitive [...] Having said that, of course there is something missing; however, I cannot say all is lost..." (MHE2)</p>
--

Table 6.4
It is almost the same

Furthermore, these repeated phrases were also used by MHEs while describing remote communication sessions requested by patients at *times of crisis*, thus, making the theme of *being there, being present, being supportive* even more concrete. Within the framework of my analysis, the code *times of crisis* refers to (a) events which patients experience as life-threatening (panic attacks, etc.), even if in reality they are not; (b) events which could potentially threaten the therapeutic goals (i.e., addiction relapse), or, finally, (c) psychological experiences which patients regard as difficult to manage on their own.

Finally, all MHEs unanimously supported that *being accessible* to their patients via ICT is an alternative way of *being there* for them. It is noted that, according to DramaTh1, *being there, being present* is considered a key-quality for maintaining trust. Similarly, MHE1 supported that *being there* was a quality that was highly valued by patients because it was perceived as a tangible form of *care*.

“Researcher: During a crisis, what is it that you believe the client/patient gets when they succeed in contacting you on the phone?”

MHE1: What they get is **immediate care** and this definitely reinforces their trust in the belief that **I am there** for them.” (MHE1)

At a later point, MHE1 stressed that replying to a patient’s e-mail message is useful in maintaining trust, both in the therapy process and in her as an expert. This, even in the case of a non-critical event or experience,

“in order to preserve trust in the process itself or in me, I may indeed respond to an e-mail message of three pages with one paragraph, just to show that **I am there**” (MHE1)

Similarly, DramaTh1, MHE2 and MHE6 supported that *being there* for their patients from a distance contributes to building trust:

“Accessibility is, of course, of primal importance in **building** trust ...”
(DramaTh1)

“Accessibility provided through modern media helps **build** trust, because they know that I will be there the moment I can” (MHE2)

“Undeniably, accessibility has a positive effect on our trust-based relationship. Accessibility contributes to **building a deep trust-based relationship** and so the patient understands that at hard times (refers to the time when the patient faced the challenge of addiction relapse) you support him, you love him, that this is not just a dispatching task for you [...] he gets the message that “you know ... at hard times **I am here for you!**” (MHE6)

Both psychiatrists associated the MHE’s accessibility with a patient’s level of security, confidence and wellness:

“If the other person feels that you are available in any way, be it Facebook, ‘pigeon mail’ or anything else, then they feel comfortable. They feel secure, they feel that much better.” (Psych1)

At a later point, MHE6 recounted her experience as a patient herself engaged in remote psychotherapeutic sessions via Skype with her therapist located in Canada. The *In Vivo* code, used to define words, phrases or terms used by interviewees,¹² “*being there, being present, being supportive...*” was used by MHE6 to examine the integral components of trust (i.e., support and being present), while verifying the association between the element of trust and accessibility:

“Personally, I had spent a lot of time searching for a therapist in Athens and Thessaloniki. Finally, a friend of mine recommended Dr. ****e, a therapist located in Canada, who offered Skype sessions. That relationship worked for two years and she is still **present for me whenever I ask for her help!** I had spent 2 years searching for a therapist in Greece when I found her, and I remember **that I felt such a feeling of salvation and support** when we spoke for first time ... I was so enthusiastic, so relieved ...” (MHE6)

To sum up, according to the group of MHEs *being accessible* contributes to building, maintaining and empowering trust. Accessibility, especially at hard times, is experienced by patients as a form of their therapist *being there*, which is considered an integral part of trust. At this point, it is worth stressing that an MHE, who has declared to their patient that they are not accessible in remote, is not considered by default as a non-trustworthy MHE. As MHE1 mentioned:

¹² The term “In Vivo coding” is often met in qualitative research manuals either as “Literal coding” and “Verbatim coding”

“trust does not fall apart if you honour the agreement you have made with your patient, even if you have stated that they are not allowed to call me on my mobile phone. If the patient has agreed to that, trust does not break because he knew from the beginning that I am not accessible by phone. Trust breaks down when you have declared that you are accessible, and you prove not to be.” (MHE1)

At this point, it is worth noting that MHEs utilised a variety of ICT in order to *be there* for their patients at difficult times. For instance, synchronous ICT, such as mobile phone calls and video conference applications, were utilised for handling panic attacks. Similarly, MHE2 made extensive phone calls to a patient who was threatening suicide. Surprisingly, MHE6 stressed that mobile phone calls are considered a therapeutic tool for supporting recovering addicts, not only because they act as a bridge for reaching the MHE, but also as a tool that enables the accessibility of all members of the group-therapy team. In particular, she highlighted that it is hard for a patient to achieve the desired aim of getting clean while experiencing a state of loneliness.

According to MHE6

“I used to propose to newcomers (supported recovering addicts) to develop a support network made up of older group members; the more members in the group, the more likely it would be to find the support and help they needed. We, therefore, encourage them to ask for members’ phone numbers and to meet for coffee after the group session so that they get to know each other. The desire to use comes unexpectedly and can be very intense during the initial period of treatment. It lasts from 10 minutes to half an hour. If, therefore, someone has a list of telephone numbers they can use in an emergency, i.e. when the desire is intense, they will overcome the difficult interval of persistent deprivation with less difficulty. The more emergency phone numbers they have on their list, the higher the probability of easily finding a member available for support 24/7. This is exactly why the telephone is considered a ‘therapeutic tool’ and people are advised through the use of flyers that contain the question “In this group session, how many members you did not know did you come to know and how many phone numbers have you exchanged?” (MHE6)

Apart from synchronous means of remote communication, such as video conference applications and standard phone calls, MHEs have also responded to their patients’ request for remote communication via asynchronous means of ICT, such as texting and e-mail services.

Consequently, it could be supported that what matters for the patient, and, consequently, for the quality of the relationship, is not the means employed for remote communication with the MHE, but the MHE's actual level of accessibility. As Psych1 noted:

"If the other person feels that you are available via any means, be it Facebook, pigeon mail or anything else, then they feel comfortable, they feel secure, they feel that much better." (Psych1)

At this point it should be mentioned that the element of accessibility strongly emerged while interviewing mental health experts. In a follow-up interview, it was only Pedia1 who mentioned a case in which patients let her know that, though they trusted her, they had made the decision not to visit her anymore because she was not as accessible as they would like her to be.

"There was a couple whose child I used to look after and who called just to thank me for my services, letting me know at the same time that they would like to follow a new paediatrician because -according to them- I was not quite accessible" (Pedia1)

Follow-up interviews were conducted with physicians, but unfortunately, it was not possible to revisit them for a third interview, as this was likely to be construed as annoying them.

6.6 The web of trust: integrating themes into a diagram

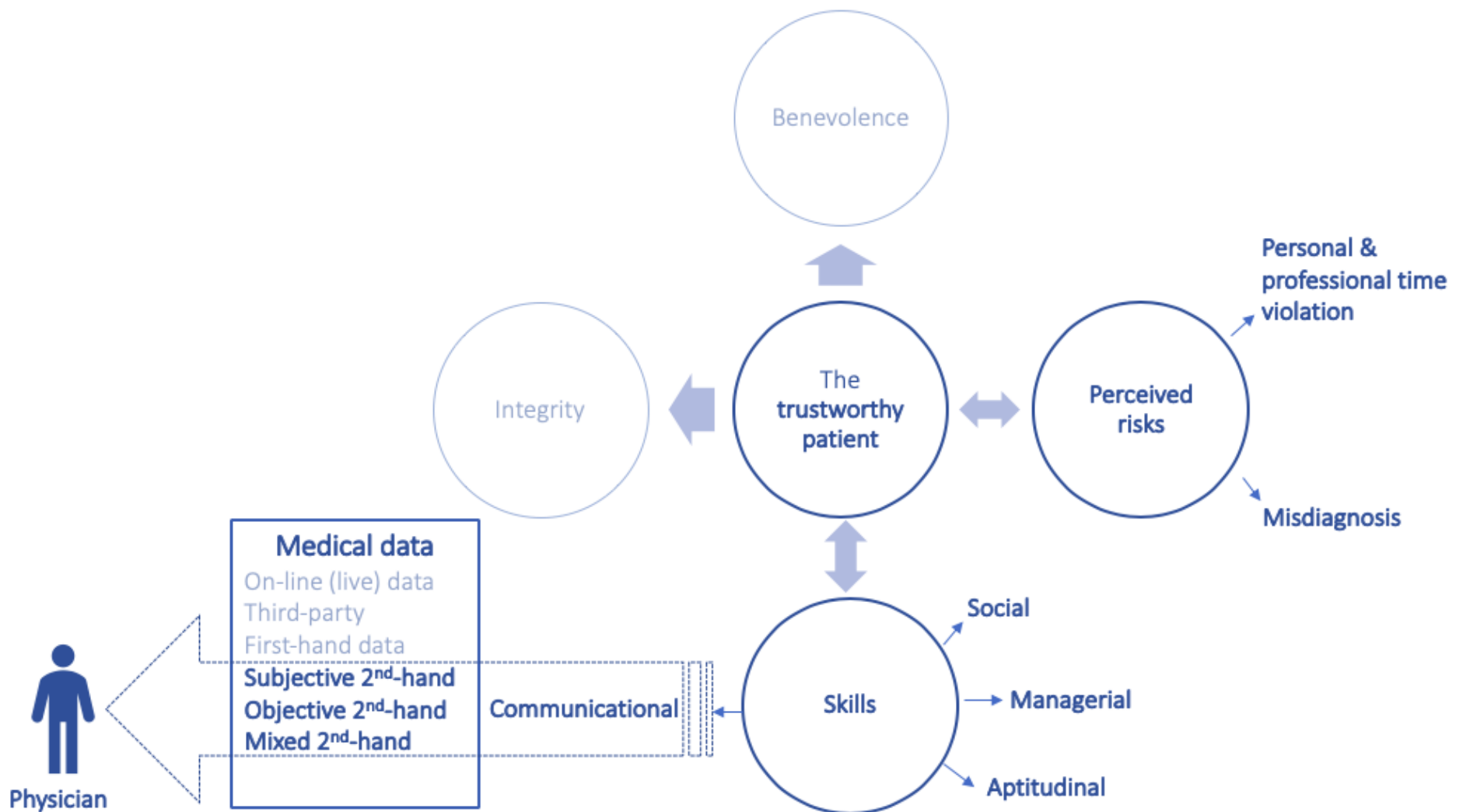
Within the framework of this chapter what has been analytically presented is the themes of the *trustworthy patient*, *(medical) data*, as well as the one of *risk perceptions*. These three clusters of data have been integrated into two *integrative diagrams* (Strauss, 1987) per group of interviewees, since they have demonstrated diametrically opposite results. As can be easily observed, the following integrative diagrams are made of the four key-components of trust, namely, *risk*, *skills (abilities)*, *integrity* and *benevolence* that have been identified by classical trust literature. In sharp contrast to the bold circles, the faded ones represent the elements of trust that have not been mentioned in the interviews or have not been mentioned to the extent of building a concrete focused code (i.e., benevolence). With regard to the integrative-diagram 6.6.2, the circles made of solid lines represent the items supposed to exist which, though, were not recognised by MHEs.

I consider that the main advantage of the integrative diagram above, which I define as the *web of trust*, is that it offers the opportunity to present in a comprehensive and clear manner how the key-elements of trust are associated with each other. As every *integrative diagram*, it offers the opportunity to incorporate the extensive tree-diagrams of the trustworthy patient, namely, the one of medical data and the one of risk. In brief, is being demonstrated in the integrative diagrams is that:

In the light of the patient-physician CMC, patient's trustworthiness (*trustworthy patient*), especially in terms of communication skills, does matter. This is because, according to physicians, any mode of CMC with their patients carries the risk of misdiagnosis -not to mention patient's safety- due to medical decisions made on inaccurate subjective 2nd-hand information provided by patients.

On the contrary, not only does patient's trustworthiness not matter for the MHEs in the light of CMC with their patients, but the TP/C does not even exist as a concept. Moreover, in sharp contrast to the group of physicians, the MHEs interviewed experienced CMC with their patients as *risk-free*, although subtle indications were found that CMC could be risky for them, too.

In Chapter 7 it is demonstrated how these three clusters of data interact with each other under the thematic umbrella of the *knowing my patient* (KMP) principle. More light has also been shed onto (a) the role of *patients' communication, aptitude, management* and, finally, *social skills* that constitute properties of the TP/C; (b) how these skills interact with each other; and, finally, (c) how they determine healthcare experts' decision on whether to open a channel of CMC with their patients or not.



Integrative diagram 6.6.1
The "Web of Trust" (physicians' perspective)



MHE

Summary table of key-findings

- 1 In the light of the patient (carer)-physician remote communication (CMC) it the aspect of *mutuality* has been unraveled in their trust-based relationship.
- 2 The *trustworthy patient (carer)* is a skillful individual with a particular set of personal qualities.
- 3 The *trustworthy patient* owns *communication, management, organisational, aptitudinal*, as well as *social skills*.
- 4 Communication skills are more prevalent in terms of incidence of codes. This was found to play a key-role in healthcare experts' decision whether to open a remote channel of communication with their patients or not.
- 5 Any decision made by physicians, based on *subjective second-hand data*, may raise concerns about its accuracy and effect in terms of patient's safety (*the risk of misdiagnosis*).
- 6 Concerns expressed by four physicians and three MHEs about the risk of their personal time being violated (*overuser risk*).
- 7 The patient-MHE paradox: MHEs recognize that their relationships with their patients are mutual, but they barely recognize the concept of the *trustworthy patient*.
- 8 In sharp contrast to physicians, MHEs experience any mode of CMC with their patients as *risk-free*, though three of them identified the risk of their time being violated by *manipulative patients* (overusers).

Chapter 7

Know My Patient/Carer

Chapter 7 demonstrates that it is of critical importance, exclusively for physicians, to be aware of the patient or carer requesting for a CMC session. In more detail, it is demonstrated that it is an unconditional prerequisite that the patient (carer) calling should (a) visit the doctor on a regular basis; (b) be trustworthy in terms of communicational; (c) have aptitudinal and managerial skills (*laid back* and *over-anxious patients*), and, finally, (d) not take advantage of the accessibility provided by the ICTs in order to violate the physician's professional and personal time (*overuser*). Furthermore, every set of skills is associated with a risk item in order to demonstrate the value of a patient's trustworthiness. Finally, great emphasis has been placed on the role of the medium's *perceived affordances*. In particular, an analysis of thirty-five events of CMC through the lens of *perceived affordances* demonstrate why the data collected by MHEs did not at all fit the codes and themes built over physicians' data.

7.1 The KMP/C principle: physicians' perspective

Every physician interviewed emphasised that it is critical for them to be aware of the patient (*know my patient*) seeking immediate answers and solutions to medical issues remotely. In brief,

none of the eight doctors interviewed would respond to any request, either for diagnosis or for medical prescription made by an unknown individual.

In fact, the phrase "*to know my patient/carers*" has been repeated from one to four times per physician, while a total of twenty-two key-statements were identified in physicians' transcripts. Given the exploratory nature of my research, it was inevitable to probe and ask for further details and clarifications about aspects of patients' physicians would be keen to know. The answers collected built an extended cluster of data that included items such as a patient's ontological perceptions (religious beliefs), psychological status, daily routine, recent and older medical history, attitude towards ICT-use and skills. Thereafter, more focused questions were asked in order to identify items connected to CMC itself.

The result of that process was the formation of the *know my patient* (KMP) theme (see Tree-diagram 7.1) consisting of the following four focused codes: (a) *a patient's regularity* in terms of visits (b) *a patient's trustworthiness* in terms of *communicational skills*, (c) *a patient's trustworthiness* in terms of *aptitude* and *management skills*, and, finally, (d) *a patient's attitude towards ICT (overuse)*. These four extensive clusters of data represent the factors that would influence a physician's decision about *how* or even *whether* to respond to a patient's request for CMC.

"Researcher: Why would you not even think about making a diagnosis remotely for a woman that you have never seen before?
ObGyn1: [...] Because, I do not know who she is"
(ObGyn1)

The KMP/C principle seems to apply not only to patients themselves, but also to carers -either formal or informal ones- who are responsible for taking care of patients lacking the ability to communicate effectively or not able to take care of themselves and make decisions for their own benefit (i.e., infants or elderly people suffering from dementia). As Paedia1 stressed:

"The paediatrician should filter who the parent calling is" (Paedia1)

Each of the four items comprising the KMP/C theme is thoroughly analysed in the following paragraphs offering an insight as into what it means for physicians to know their patients. Greater emphasis has been placed on patient's communicational, aptitudinal and managerial skills, as well as the patient's attitude towards ICT, since all these items are key-properties of a *trustworthy patient*. Integrative diagram 7.1 demonstrates how the codes built up the KMP/C theme supporting the chain of evidence.

7.1.1 A patient's regularity in terms of visits

"you must be rather reserved when you respond to incoming calls from patients who are either unknown to you or who are known but **not regular** in their contacts" (Diab1)

As it has already been underlined, physicians would never remotely offer diagnosis, medical guidance or treatment to individuals whom they *do not know*. This does not necessarily mean that they would not hesitate to remotely offer medical guidance to patients who they had

examined in the distant past. It is also of critical importance for physicians to be aware of their patients' recent medical status, i.e., to have met or examined the patient at least once in the recent past.

"To a client who is a **regular** contact and whom I trust, I would give the diagnosis (remotely), if she didn't need further testing." (ObGyn1)

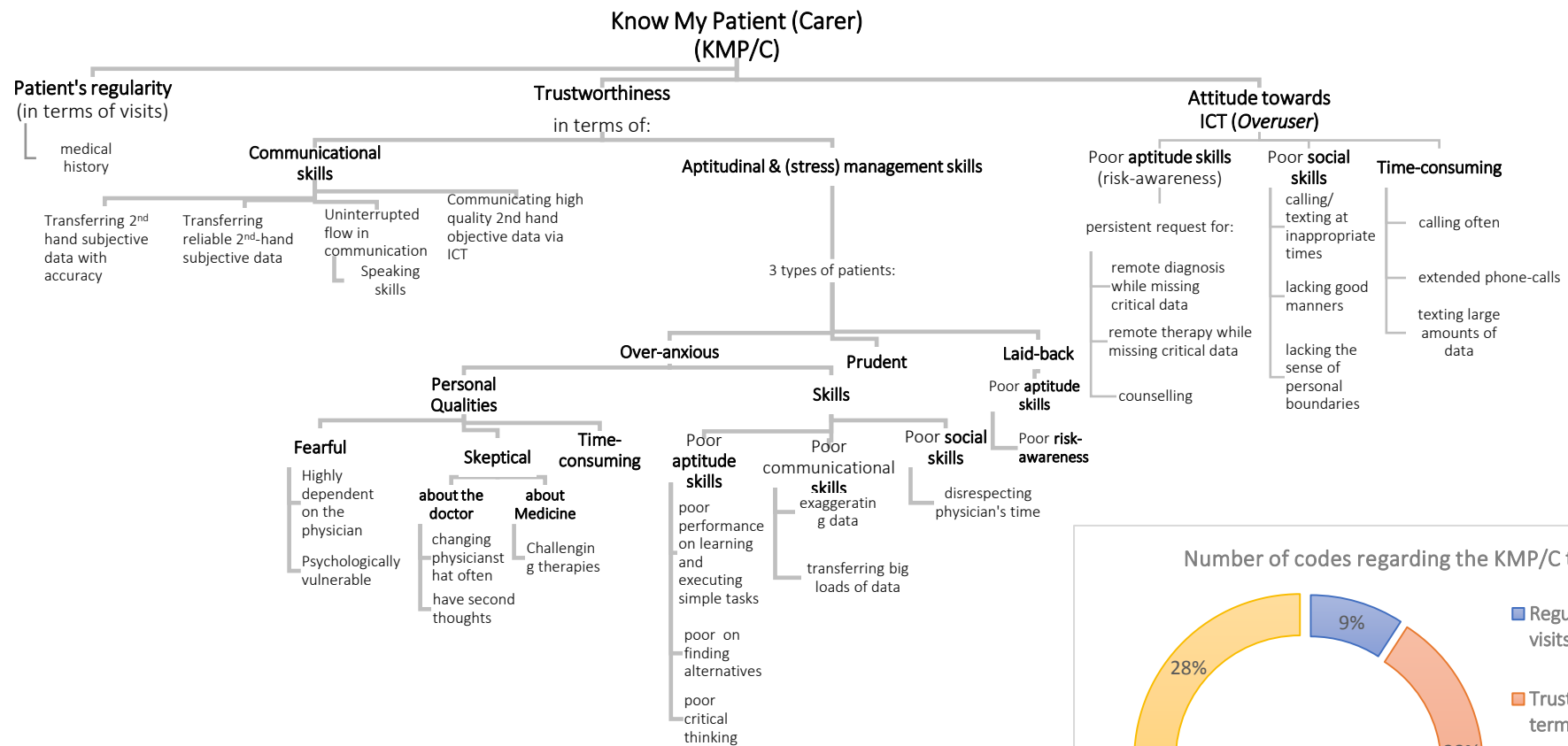
A closer look at the statement by ObGyn1 reveals that she would respond neither to an unknown individual seeking medical advice remotely, nor to one who is not a *regular client*. The aspect of *regularity* also seems to play a crucial role in the parent-to-paediatrician remote communication:

"[...] **with someone I haven't seen for a long time** and who comes and says to me "we have these issues", over the telephone or electronically, I would be very reserved, or even **refuse** communication." (Paedia1)

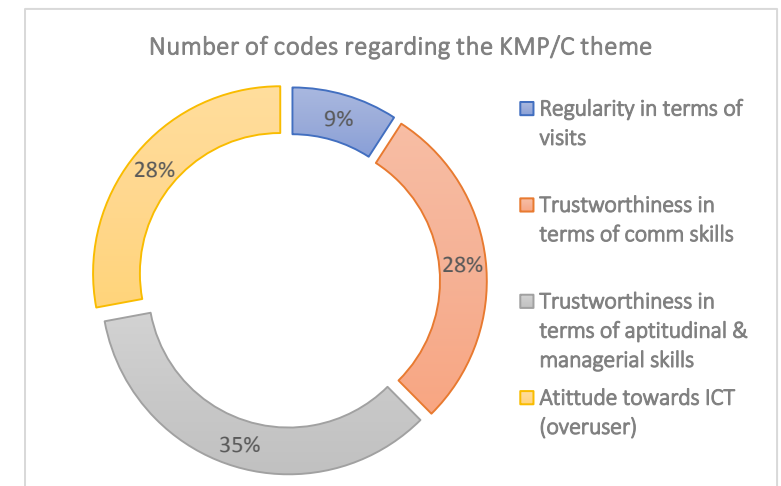
At a later point, Paedia1 emphatically stated that she would refuse a parent's request to sign any health certificate, if she had not examined the child within the last 7 months, on the grounds of not knowing the child's recent medical history. Patients who request a diagnosis or treatment options via remote communication without having recently been examined, do not get a response, unless they visit the physician for a clinical examination.

"My response was "No! No exception can be made!" And there are two reasons why I did not make an exception. One is that it was so **much later after** my working hours – there comes a point when such a time limit line has to be drawn." (Paedia1)

At this point it is worth noting that the emphasis placed by physicians over a patient's medical history signifies the need for building an electronic health-record database instead of keeping medical record hard copies. Such technology would offer physicians access to patients' primary or secondary medical health records contributing to *knowing the patients*, even if they have never examined them in the distant or recent past. It might be possible that such technology might minimise the risk taken in the light of CMC.



Tree-diagram 7.1



As expected, physicians are not in favour of responding to requests for remote communication made either by unknown patients seeking a diagnosis, or by patients who are not ‘regulars’ because crucial data concerning such a patient’s recent medical record are unavailable. It is imperative for physicians to know their patients’ medical history before they undertake remote implementation of any medical act (i.e., diagnosis, consultation treatment plan, etc.). However, regular visits not only help physicians become aware of their patients’ medical-history, but they also help them get to know the range of their communication, aptitude, management and social skills. It is highlighted that such skills are assessed by physicians as “must have”, since they contribute to the minimisation of the two risks identified in the previous chapter, namely, the risk of misdiagnosis and the risk of their personal time being violated (*overuser*).

7.1.2 Patients’ trustworthiness in terms of *communicational skills*

“There are many times when some of my colleagues refuse to offer medical advice over the phone [...] The truth is that, most times, I give medical advice over the phone when I see that I trust the patient [...]”
(Phys1)

It is crucial for physicians to *know the patient* calling or sending the SMS requesting a diagnosis, a consultation or a change to their medication. In particular, one of the factors, *inter alia*, that physicians want to make sure that the patient (or carer, respectively) calling or sending the SMS is *trustworthy*. However, as mentioned in the previous chapter, *trustworthiness* is a multifaceted concept involving very specific personal qualities and skills. The inevitable question emerging at this point is what aspects of the *trustworthy patient* seem to affect a physician’s decisions about *how* to respond to the patient’s requests for remote communication or *whether* they should open a channel of remote communication.

It has been found that physicians hesitate, or even refuse, to provide remote guidance or diagnosis in cases where they judge that the patient or the carer does not accurately transfer reliable, subjective, second-hand data considered crucial for reaching a safe and effective decision.

Though not all interviewees agreed on the same qualities and skills of the *trustworthy patient/carers*, they all emphasised *communicational skills* considered a necessary prerequisite

condition for opening a remote channel of communication. As both Phys1 and Paedia1 stressed:

“[in remote communication] the physician is exposed because he/she trusts the one who gives the information” (Phys1)

“The paediatrician should filter who the parent calling is or what bits of information that parent is sending” (Paedia1)

Similar to Paedia1, Paedia3, responding to my question “*who would you consider the most inappropriate patient/carers for remote communication and why?*”, emphasised the role of *speaking skills*:

“Individuals who are not native Greek speakers. For example, I take care of the child of a couple; the mother comes from Poland and her speaking skills in Greek are not good enough for me to consider appropriate for remote communication; there are some individuals whom I personally consider unreliable, because they can’t accurately describe what is going on.” (Paedia3)

Phys1 emphatically stated that patients who *miss out critical data to report* are considered inappropriate for remote communication for medical purposes.

“Phys1: [what was actually happening] was a far different situation from what she had described to me over the phone. Her health status was quite urgent. She could have ended up with an inflammatory embolism. The thing is that even her carer had not mentioned that it was her whole leg that was swollen, not only her ankles! [...]

Researcher: Would you be more reserved in your communication over the phone with such a group of patients in the future?

Phys1: 100%! No second thought about it at all! I would not rely solely on what they are writing to me via an SMS or on what they tell me over the phone!” (Phys1)

Surprisingly, though Ophthalm1 holds the view that physicians should not be sceptical towards their patients, a view also held by Rogers (2002), she stressed the importance of *transferring data accurately* in remote communication:

“A friend of mine called me and told me “my eye aches!”. I personally avoid giving diagnoses based on what a patient tells me over the phone. [...] I want to see what is happening with my own eyes [...] because there are many ways to describe something [...]. Under certain circumstances someone may be seeing colours, flashes, even shapes or faces due to several syndromes. The most important thing is that the patient should not describe to you what he/she is feeling using inaccurate words.” (Ophthalm1)

ObGyn1 clearly stated that she would prefer responding to patients’ requests for the remote resolution of a medical issue only when she *knows* them, and she has observed that they (the pregnant women) are able to *transfer reliable subjective second-hand data* in an *accurate manner*:

“I would prefer an SMS from a patient whom I know well, so that I know that out of the 5 things she has told me, all 5 are true, correct and reliable and so, in my turn, I can tell her 2 things she must do; the issue can be resolved, and we can move on.” (ObGyn1),

while, at a later point, she stressed that the concept of the *trustworthy patient* is interwoven with *transferring reliable subjective second-hand data accurately*:

“remote communication carries the risk of misdiagnosis due to false subjective observations made by an individual I do not consider trustworthy” (ObGyn1)

A closer look at Paedia2’s statement below reveals that carers who lack the skill to *accurately describe* a situation have a negative impact on the paediatricians’ decision to respond to a remote request for a diagnosis.

“If I have had issues with a parent’s trustworthiness or ability to describe accurately, then I would politely challenge him/her saying that ‘If I don’t see the child, I can’t tell. You must bring him/her to my office’ ” (Paedia2),

while, similarly, at a later point she stresses that:

“Yes, it has happened. Not getting reliable data on the phone and so inviting the parents and the child to my surgery.” (Paedia2)

In a similar manner, Diab1 recognised the importance of effective *communicational skills* in remote communication between the physician and the carer, emphasising *accurate data-transference*:

“Please, understand that we often deal with older people who have dementia, either incipient or fully-blown. That is where the relative (in the role of a carer) needs to be reliable, as it is they who share the information.” (Diab1),

while, at a later point, she stressed that:

“Personally, I talk to all my patients on the phone, but I do not accept every response with equal merit” (Diab1)

Finally, three out of the eight physicians interviewed referred to the ability of the TP to *communicate high-quality second-hand objective data* via ICT. As Paedia 2 mentioned:

“The parent can’t convey the information I need for an accurate diagnosis using a photograph.” (Paedia2),

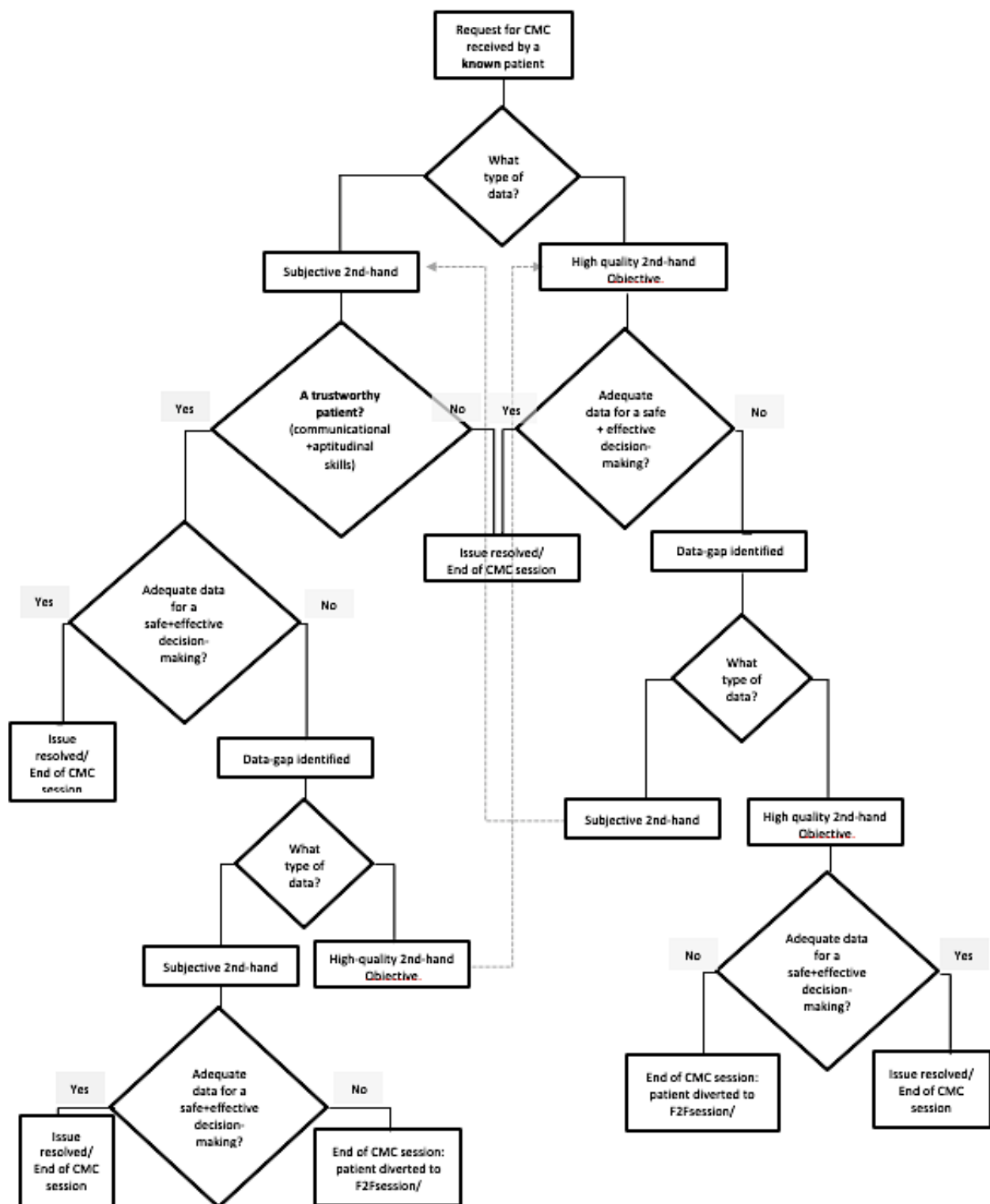
while at a later point she underlined that:

“I trust neither the medium nor the photographer (user)” (Paedia2)

Similar to Paedia2, Dent1 mentioned that:

“the angle from which the photo has been taken or even the shadows captured due to bad lighting are both factors that may lead me to miss critical information” (Dent1)

In brief, it has been observed that all physicians highly value patients’ communicational skills in transferring reliable data accurately during remote communication. In other words, it seems that patients and carers who lack the skills associated with accuracy in transferring data are excluded, or even blocked, from active remote communication. However, it should be highlighted that physicians would not undertake the risk of remotely implementing any medical act requested, even for their *trustworthy patients*, if they determined that the medium employed by the patient for transferring any relevant data was not suitable to depict the complete set of data required for effective and safe decision-making.



Flowchart 7.1.2

Flowchart 7.1.2 demonstrates the value of the TP/C's *communicational* skills through an algorithm that exhibits the physicians' decision-making process in response to a patient's request for CMC. The element of *medical-data-gap* mentioned within the flowchart is defined as the amount of data that should be collected for making a safe/effective decision minus the maximum amount of data that was finally possible to be afforded and collected via the ICT.

In particular,

a (*medical*) *data-gap* emerges when healthcare experts assess that the medium/ICT employed for CMC and, therefore, medical-data-collection and assessment, is not capable of *affording* to transfer the necessary cluster of medical data necessary for an effective and, above all, safe medical decision to be reached.

7.1.3 Patient's (carer's) *aptitudinal* and *managerial* skills

"I deal with mums who are so laid-back ... in the case of a phone call you must remember who is who." (Paedia1)

Paedia1's quote indicates how important it is for her to *be aware of who* is the parent calling and what the patient's profile is in terms of *risk awareness* (placed under the focused code of *aptitudinal skills*) and *stress management skills* (placed under the focused code of *managerial skills*). A patient's profile, in the terms mentioned above, seemed to influence a physician's decision about *how* or even *whether* to respond to an incoming call or SMS sent by a patient. A range of both patients' and carers' groups emerged during the analysis stage based on their aptitudinal and managerial profile, namely: *laid-back*, *over-anxious* or *prudent*.

In brief, the *prudent patient/carers* (a) usually *respects the physician's personal and professional time* by making phone calls only when there is an actual problem; (b) demonstrates *risk-awareness*, and, thus, s/he also (c) saves time. A more detailed picture of the prudent patient's profile could come from the analysis of *laid-back* and *over-anxious patients/carers*, whose profiles are analysed in the following paragraphs and demonstrate diametrically opposing properties.

Laid-back patients/parents stand out because they are lacking either the willingness or the skills to identify risks associated with health status. In other words, they lack the *aptitudinal skills of being risk-aware*, which could probably explain why they do not take a physician's guidance seriously. A plausible explanation offered by Diab1 was that such patients usually behave in such a way because they are in a state of denial, i.e., they refuse to accept their health status.

“Look, someone who is really relaxed is, in a way, unreliable, meaning that s/he is not taking what you say seriously. That is the laid-back patient; someone who will underestimate the illness, the disease or the issue at hand.” (Diab1)

Patients and carers are also considered as *laid-back* (or *dangerous* according to Paedia3) when they lack the ability to identify risks considered easily detectable even by ordinary people who lack medical training:

“the dangerous mum is unable to correctly assess a situation [...] for the dangerous mum, a temperature of 39.3°C is not considered to be critical or, else, high fever.” (Paedia3)

Paedia1 mentioned that being in a therapeutic partnership with *laid-back patients* obliges her to make an additional number of follow-up phone calls to the child's parents, since she does not consider them *trustworthy*. In other words, it is the parents' lack of risk-assessment skills that obliges her to spend more time making phone calls than she would normally do.

“I often ask my assistant to call laid-back parents back in order to get some more information about how the child is getting on, because I want to be sure that they are not sipping their drinks while the child is suffering from meningitis” (Paedia1)

In brief, the *laid-back parent* lack *risk awareness* to the extent that obliges either physicians themselves or a nurse to make several follow-up phone calls to ask about the child's health, because the carer is not considered trustworthy. So, a *laid-back parent* in the role of the carer is found to be costly in terms of time and human resources.

In addition to the group of *laid-back patients*, the category of *over-anxious* or *excessive* patients has emerged.

“I deal with mums who are stressed to such an extent that they will exaggerate things! In the case of a phone call you must remember who is who!” (Paedia1)

Both *over-anxious (excessive) patients* and *carers* are distinguished for (a) *being fearful* (lacking stress-management skills); (b) *being sceptical*, and (c) *time-consuming* (i.e., taking up much more time than a *prudent* patient). Moreover, *over-anxious patients/carers* have poor (d) *aptitudinal*, (e) *communicational* and (f) *social skills*, which are analytically presented on the following page (Tree-diagram 7.1.3). All physicians unanimously reported that *over-anxious* patients and carers are *not* necessarily unsuitable for remote communication, due to their tendency to exaggerate actual symptoms, but they all appeared to employ the same strategy in handling phone calls from *over-anxious* patients. The strategy comprised the following stages: (a) leading the conversation using targeted questions; (b) demonstrating patience; (c) spending more time than usual; (d) cross-checking patient’s verbal data with theoretical knowledge and clinical experience.

More specifically, Dent1 and Paedia2 adopted their response strategy over the phone based on a patient’s or carer’s very personal risk awareness and stress management skills. In particular, *being aware of* their patient’s profile in terms of handling fear helped them avoid extended phone calls through close-ended questions and time boundaries that Paedia2 imposed.

“Researcher: I am really keen to know how you handle cases when you remotely receive totally subjective data

Dent1: [...] it really depends a lot on the patient. During the visit and during an operation, if you see that the person is rational and there is a normal anxiety level for their condition, you will allow more space to listen to them. If the patient jumps without you even touching them because they think that you touched them, you just ask more questions, you try to filter the information [...] And you cut off [!] any further discussion at that point.” (Dent1)

As expected, the strategy applied by physicians in response to *over-anxious patients’* request for remote communication is also applied in response to requests from *over-anxious carers*. According to Paedia2:

“I don’t consider over-anxious patients as unreliable. In fact, I can filter the information better. The hard part is that you try to remove the exaggeration from all that is being said, to correctly direct the question because you reach a point when you say, “hold on a minute”, because you see that they are lost and I would rather have them answer my own questions. “Wait – I will ask you something and I want you to answer me so that I have a picture of this.” (Paedia2).

In sharp contrast to the *over-anxious* carers, Paedia1 and Paedia2 supported that parents who can manage simple tasks, such as their kids’ low fever (prudent parents), in an effective way, tend to make fewer phone calls and, therefore, take up less of the physician’s time. According to Paedia1, the parents’ ability to efficiently respond to simple tasks is highly appreciated by both paediatricians and affects their decision as to whether to answer an incoming phone-call or not:

“(the trustworthy parent is one who) knows how to manage one or two things so that, when I see my phone ringing, I’d say “Parent X is calling, I need to answer!” (Paedia1)

Finally, Paedia1’s statement that she used to process data sent by a parent she trusts in a completely different way from data sent by one she does not, summarizes physicians’ attitude towards ICT –both asynchronous and synchronous- as a means for remote communication.

However, it is worth highlighting that though *exaggerating data*, or else lacking the skill of *transferring data in an accurate manner*, is one of the *over-anxious* parents’ common features, Paedia1 does *not a priori* consider *over-anxious parents* untrustworthy and, therefore, unsuitable for remote communication. Paedia1 argued that they are not unreliable in terms of communicational skills because *over-anxious* do not tend to *miss any critical piece of information*, an item which is also considered an attribute of the *trustworthy patient/carers*:

“Manipulative¹³ types cannot break this relationship [...] they are trustworthy. If you handle them correctly, they are trustworthy. They just need a bit more time and more calmness. But they are trustworthy in the sense that they will give you all the information. And when I say all, I mean all!” (Paedia1)

¹³ Paedia1 refers to the over-anxious parent either as manipulative or as over-anxious.

Nevertheless, for Paedia1 an *over-anxious parent* may come under the category of an *untrustworthy carer* when s/he does not comply with instructions that phone calls should be made only at instances of an unmanageable and, therefore, risky situation. In other words, an over-anxious parent becomes untrustworthy and, therefore, inappropriate for remote communication when s/he becomes an *overuser*, i.e., someone who uses ICT as a Trojan horse ready to invade to physician's personal and professional time.

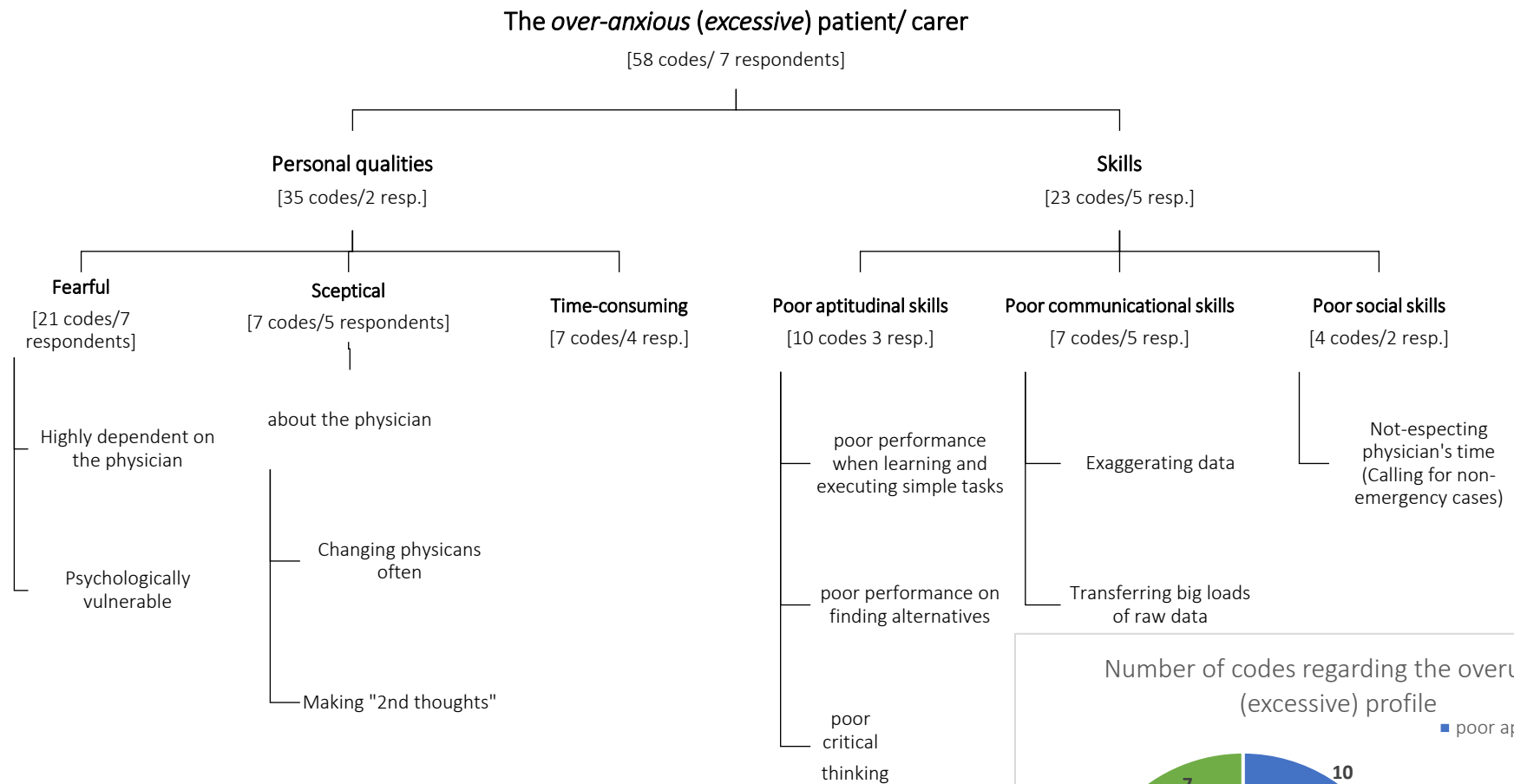
"...but when consecutive phone calls keep coming up, over and over again, then the trust-based relationship suffers on both sides."
(Paedia1)

The following paragraph introduces the concept of the *overuser* and how his/her properties determine a physician's decisions on *how* or even *whether* to respond to a request for remote communication for medical purposes.

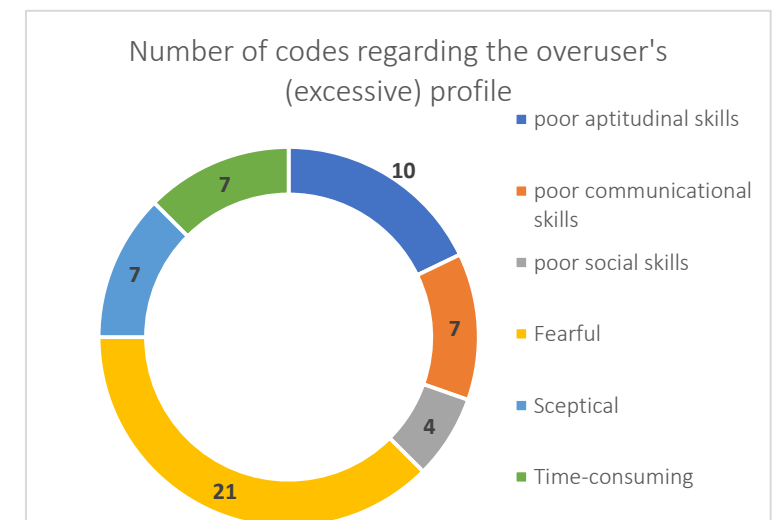
7.1.4 Patients' attitude towards ICT (*overuse*)

One of the terms and concepts that stood out during the data-collection and analysis stages was *overuse*. Before presenting the initial codes that built up the *overuser*, it is worth noting that it was not only physicians that contributed to the development of the *overuser* but MHEs, too. More specifically, all physicians, except Ophthalm1 and Phys1, used this term to express their annoyance with certain ways in which ICT was used. All referred to individuals who make extensive use of mobile phones, both in terms of (a) frequency and (b) duration of remote sessions in regard either to speaking or to texting. Indeed, *overusers*¹⁴ (Tree-diagram 7.1.4) have (1) *poor aptitudinal skills (poor risk-awareness)*, as well as (2) *poor social skills*. *Poor aptitudinal skills* are reflected on *poor risk-awareness*, account for *persistent requests* for both *remote therapy* and *diagnosis*, while necessary medical data are lacking.

¹⁴ Often called *annoying* or *manipulative*



Tree-diagram 7.1.3
The over-anxious (excessive) patient/ carer



As Paedia1 stressed:

“Overuse happens when someone wants to elicit information, diagnosis and treatment remotely, although I cannot be 100% safe for myself or for the child [and] what puts me in an awkward position is the request for a therapeutic regimen when technology (ICT) is incapable of conveying to me all necessary information.” (Paedia1)

Poor aptitudinal skills also account for a significant number of phone-calls regarding non-emergency matters.

Two different groups of healthcare professionals were identified on the basis of their elasticity of personal boundaries. According to the first group (Paedia1, Paedia2, Paedia3 and ObGyn1), patients and carers are allowed to make use of synchronous means of communication (i.e., phone calls) out of office hours only when they are facing a critical and, therefore, unmanageable situation. This attitude towards ICT use is perceived by a group of doctors as behaviour which demonstrates respect for their personal life and it is highly appreciated. As ObGyn1 mentioned:

“I would not feel bad if it was indeed something urgent. For example, a pregnant woman with a haemorrhage or a young girl in severe pain, which may, for example, be an ectopic pregnancy and needs to go into the operation room, would not bug me at all. I would... not feel happy but, rather, content that she is to be congratulated on knowing when to call and knowing what to say.” (ObGyn1)

Similarly, Paedia2 and Paedia3 stressed that they would not feel their personal time was being violated by receiving a call from risk-aware parents, even at inappropriate hours:

“A baby with a high fever will have some difficulty, or s/he will vomit; this is an urgent case. And it is normal to disturb you [for advice] once or twice [...]; what is not urgent is to be asked by someone whether they should include broccoli in the child’s soup.” (Paedia2)

“When I see a call from a prudent mum -or else a mum who is not fearful- at 03:00 am, I know that it is certainly something urgent! On the contrary, if I receive an incoming SMS from a mum at 02:30 asking for an appointment because her child is ill, I will keep in mind that the next time she calls me at midnight it will be for a stupid reason!” (Paedia3)

Paedia1, similarly to Paedia3, referred to the category of *normal or prudent couples (parents)* and their attitude towards ICT as a communication tool with physicians:

“Normal couples are a single category of carers who don’t take up of your time unnecessarily. They will call you only for a specific purpose, and this is something that you find out during the first three to six months after the baby is born” (Paedia1)

At this point, it is worth mentioning two extreme cases related by ObGyn1 and Paedia1, who, not only left their patients’ phone calls unanswered, but were, even, forced to block their phone numbers. It should be underlined that both attributed their extreme reaction to all the criteria of the *overusers’ category*.

“Yes, it has happened; I did **block** one of my patient’s phone number due to the large number of her phone calls [...]; she used to visit me in my office in the morning, then call me in the afternoon of the same day asking me the same things again and again [...]; that happened more than five times at the diagnosis stage, even before we got to the treatment stage! And all this was ... you know ... kind of excessive” (ObGyn1)

Similarly, Paedia1 made extensive reference to a case when an *over-anxious* mum used the mobile phone like an *overuser*:

“On Friday night, the child of an over-anxious mother got ill. I had seen the child who had come along with her dad to my office; I had instructed them about what treatment should be followed, while stressing that there was a good possibility that the cough might be psychogenic, a kind of habit cough. I told Dad what should be done so as to exclude or verify that diagnosis. Yesterday, at 23:58 I received a phone call as I was returning from my office and getting ready to park the car and enter my home. It was her mom! I did not answer the phone. I thought to myself “Enough is enough!” Because, if you do not say “Enough is enough!”, it will do no good to yourself or your job. On the one hand, you should show empathy for your patient’s anxiety, but they should also think that “it is Saturday night” and so the doctor might be drunk, having sex, chilling out or at a concert with friends with his mobile phone on silent. She called me 5 times! So, after her first two unsuccessful attempts to talk to me, she should think “It’s OK ... he probably did not hear the phone...” I can’t really understand the fifth call, because, if it was something really urgent, she should have taken the child to hospital! That is why I **turned off** my mobile phone after

the fifth call! I was afraid that she might be calling me even at 04:00!”
(Paedia1)

At a later point, he mentions:

“As you can imagine, I would like to get rid of these parents as soon as possible, because there are a lot of cracks in our relationship.”
(Paedia1)

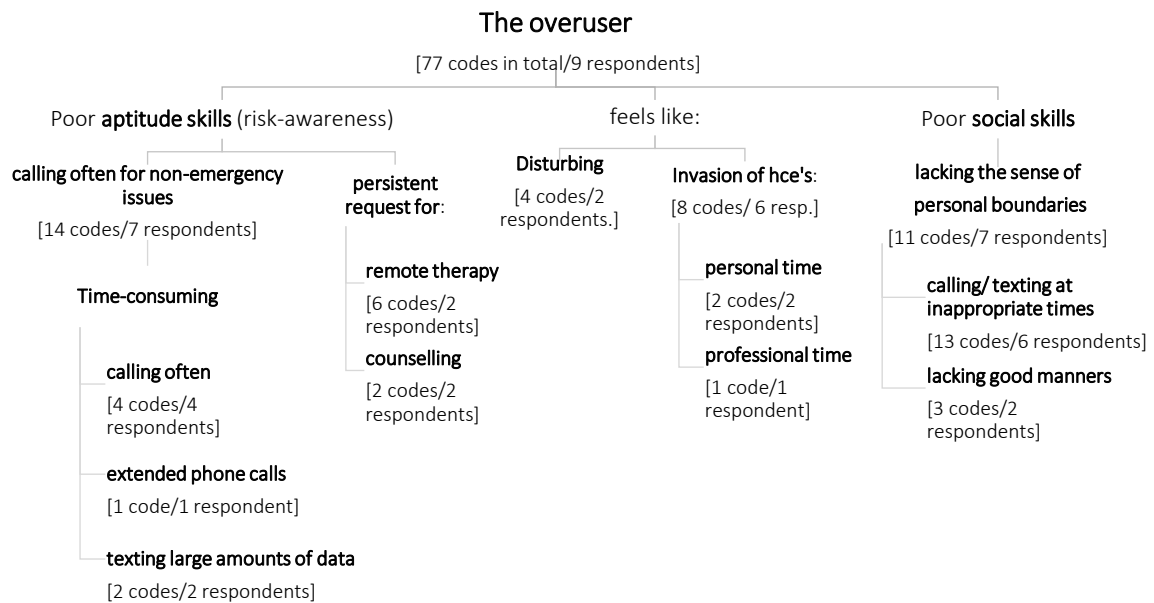
Although Paedia1’s and ObGyn1’s reactions to consecutive incoming calls from *overusers* were not shared by other physicians, the latter indicated that overuse on the part of the patient could well lead to the termination of their therapeutic relationship with their doctors.

What is more, there is a group of physicians who decide *how* or *whether* to respond to a remote request when they consider that the patients are abusing this mode of communication. Yet, there is group of physicians (namely, Dent1, Ophthalm1, Dent1 and Phys1) who support that physicians ought to show understanding and empathy for both patients and carers, because the latter lack the expertise to identify what is critical and what is not. Consequently, physicians should answer every call from patients or carers, ignoring their habits as ICT users.

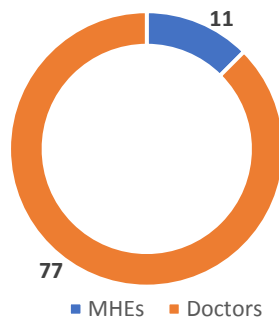
“Look, when you share your mobile phone number with your patients, you should be aware that they may call you even at times when you, as a healthcare expert, would not consider the situation an emergency. The thing is, for your patient, it is an emergency! [...] I have often felt that my personal time has been violated. However, you can’t do anything about it! Otherwise you’d be better to turn off your mobile phone.” (Diab1)

One of the most surprising findings was that Phys1 does not block remote communication from his patients who *overuse* ICT. Instead, he takes advantage of the geographical distance that ICT provides, as a defensive strategy against the *overusers’ Trojan horse*. In fact,

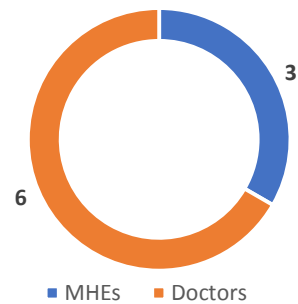
“I prefer to communicate with them (*overusers*) remotely because, regardless of the number of times you examine them, they will keep on calling you, asking for a clinical examination without going through a critical condition for their health ... something like that would be a waste of time ... and you can’t charge them every single time they ask for a clinical examination! So, I prefer to calm them down by phone, instead of asking them to visit me in my office. I prefer to resolve such cases on the phone.” (Phys1)



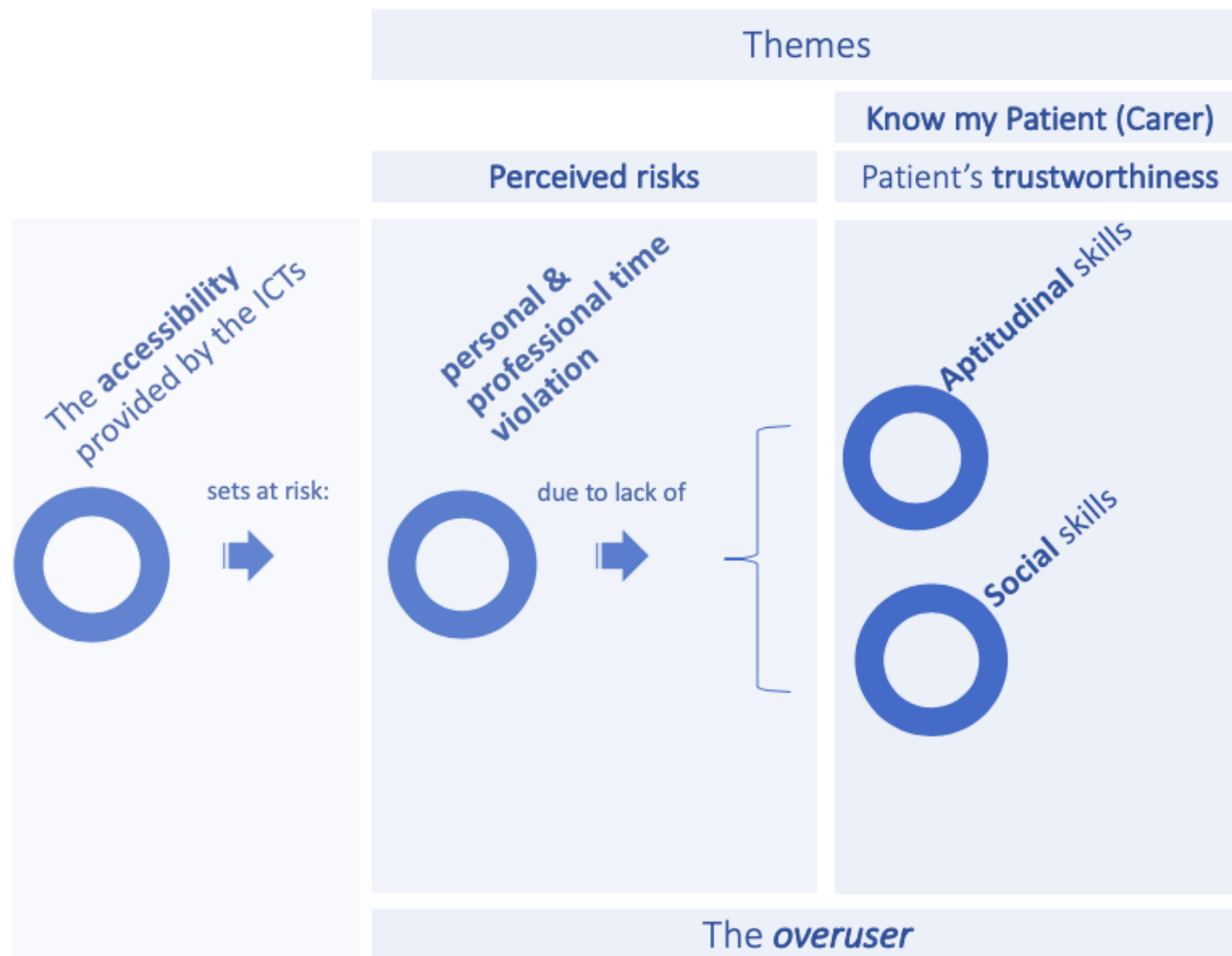
Number of initial codes built up *the overuser*



Number or respondents regarding *the overuser*



Tree-diagram 7.1.4
The overuser (manipulative) patient/ carer



Flowchart 7.1.4

It seems that the heterogeneity detected in managing both personal boundaries and *overusers* could be attributed to differences in the way physicians, as individuals, perceive reality and value risk. However, there are insufficient data for supporting any theory, emerging or established, at this stage of the research. In brief, it became apparent that excessive use (*overuse*) of phone calls on the part of the patient may cause annoyance to physicians and, hence, make them become more selective when answering patients' incoming phone calls, not to mention blocking some of them. On the other hand, there were physicians who supported that healthcare experts should be more flexible in terms of boundaries and, hence, answer every incoming phone call, even if these are coming from patients who are known to be fearful and, therefore, time-consuming.

To sum up, it is important for physicians to be aware of patients in terms of their *attitude towards ICT* before they respond to their requests for CMC (flowchart 7.1.4).

7.2 The *know-my-patient* principle (KMP/C) from the MHEs' perspective

Similarly to physicians, mental health experts (MHEs) reported that it is also important, yet not an unconditional prerequisite, for them to be aware of their patients' profile before they engage in remote sessions. In fact, five out of the eight MHEs interviewed stated that it is important for them to have met the patient at least once, face-to-face, either in regular or in group sessions, before they decide to engage in remote therapeutic sessions via video conference applications. Even in cases when MHE1 and MHE3 did not *know the patients* who requested remote sessions, they relied on information provided by *trustworthy third-parties* who were either current or ex-patients and who acted as mediators. Inevitably, the question emerging at this point is:

“What are the factors and data MHEs use to assess their patients before they decide whether to replace or complement regular face-to-face sessions with video-therapy sessions?”

It is important for MHEs to be aware of (a) their *patients' psychopathology in terms of risk*; (b) whether remote sessions is the only option due to *geographical, monetary, weather, physical* or even *social constraints*, as well as (c) whether remote communication *contributes to the*

achievement/effectiveness of therapy or undermines it, before they decide to engage in regular video-therapy sessions or not (Flow-chart. 7.2.1).

With regard to the first selection criteria for video-therapy sessions (VTS), it is critical for MHEs to be aware of their *patients' psychopathology in terms of risk*. All MHEs unanimously agreed that they would be opposed to starting a round of video-therapy sessions with individuals suffering from a wide range of major mental disorders (i.e., suicidal tendencies, severe depression, etc.), because the likelihood of having those types of patients under physical *control* at times of crisis would be missing.

“Severe depression needs touch. I could not have Skype sessions with patients suffering from severe depression because **I have no control** ... there is a fear of suicidal tendencies because I am not there! You see? I am far away behind a screen.” (MHE2)

Similarly, DramaTh1 mentioned that

“I would not have Skype sessions on a regular basis with patients suffering from serious disorders or with patients who have disorganised personalities, because it is my personal feeling that the situation would be **under** less **control** than if there were physical proximity.” (DramaTh1)

Once MHEs are aware of their patients' psychopathology, they assess whether the option of remote sessions is the only one due to *geographical, monetary, weather, physical* or even *social constraints*, as demonstrated below:

“In small towns, there is still a lot of stigma and prejudice against people searching for psychological support and therapy. This is why people living in such areas seek help in big cities, where they are unknown. It's been my experience to refer patients to my colleagues who practise in Thessaloniki, a few miles from the patient's location. Due to geographical constraints, my colleagues deemed face-to-face sessions impossible and, therefore, they started therapy sessions via Skype. According to my colleagues, the remote sessions ran smoothly...” (MHE7)

In other words, MHEs assess whether the patient's request for remote therapy sessions is due to a set of practical constraints or to a *reluctance to commit to a face-to-face relationship*. In

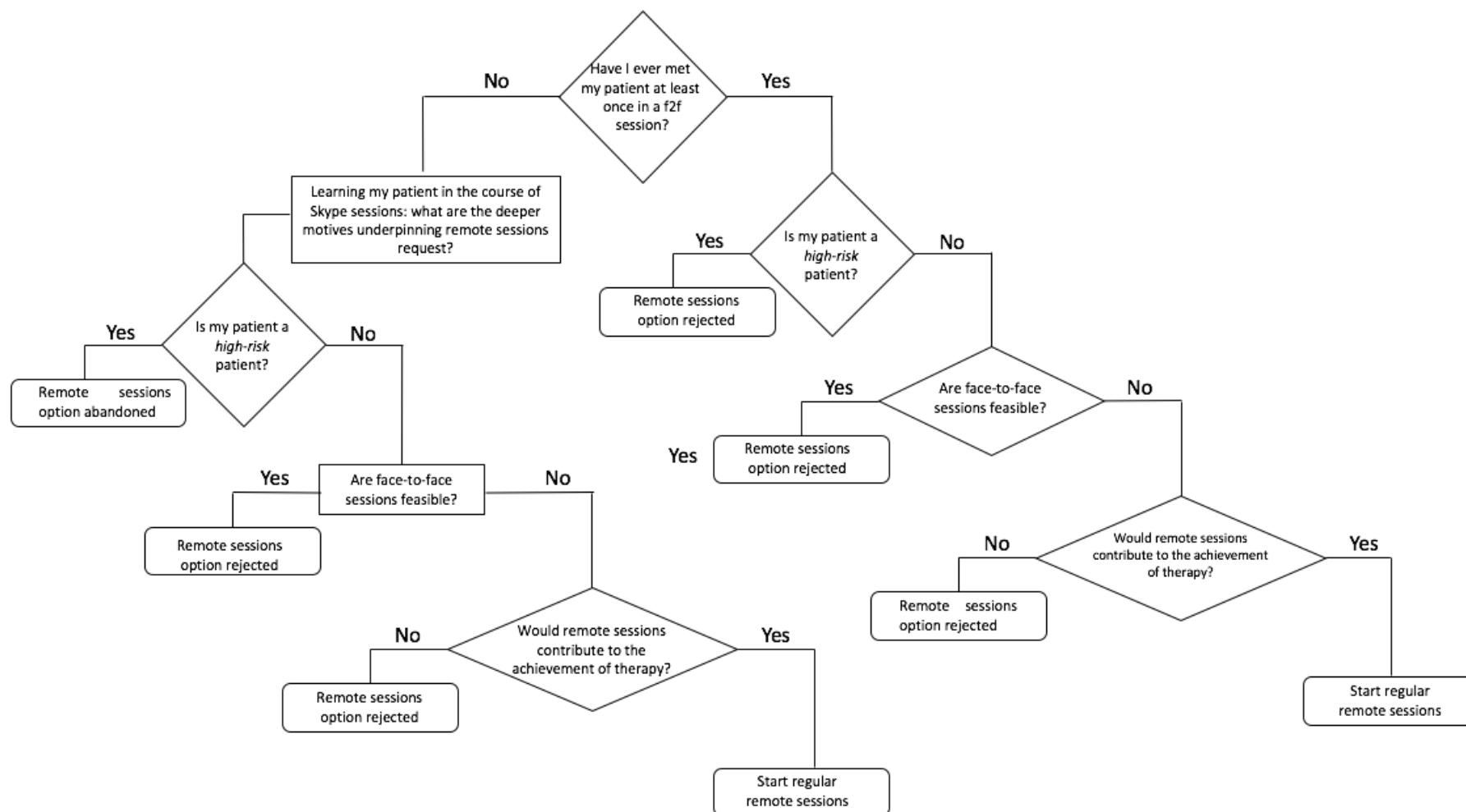
cases when face-to-face sessions are feasible, MHEs do not accept remote sessions as an equivalent alternative.

“When the patient found out that the Skype sessions helped him, as he used to have panic attacks with agoraphobia and did not want to get on the bus, he started cancelling face-to-face sessions, telling me: “You know what, let’s Skype today”. This happened three times, so I put a stop to Skype, telling him: “We will continue on Skype only when your health condition does not allow us to meet.” (MHE2)

Finally, MHEs make assessments based on their patient’s individual psychopathology in order to decide whether remote communication *contributes to the achievement/effectiveness of therapy* or undermines it. According to MHEs, there are types of disorders or addictions which demand proximity and physical touch. Therefore, any mode of *remote* communication is, by default, considered ineffective, since it does not contribute to the achievement of the therapeutic goal.

Here, the goal is to help people move beyond the comfort zone of their personal space and build actual/real relationships. Instead, remote modes of therapy perpetuate distance and, therefore, isolation, which is a central issue to be resolved when dealing with addiction, for example.

To sum up, it is important for MHEs to be *aware of their patients’ psychopathology in terms of risk*, as well as of the nature of their patients’ issues or disorders before they make a final decision about replacing regular face-to-face sessions with remote sessions via video conference applications. Once geographical, weather, physical or social *constraints* do not preclude patients from visiting their MHE at the latter’s own premises, remote sessions are not an option. Flow chart 7.2.1 demonstrates the stages MHEs go through before they decide whether to replace regular face-to-face sessions with remote ones via video conference applications.



Flow-chart 7.2.1
MHEs' decision-making process about a patient's suitability for VTS

7.3 The *perceived affordances* lens

7.3.1 The “stealth” role of *perceived affordances* in the patient-healthcare expert CMC

As demonstrated in Table 7.3, the data collected from the group of MHEs do not match those collected from doctors. In particular, the codes and themes built indicate that there is great discrepancy between the data collected from the two groups. As the key-findings summary Table (7.3) indicates, on the one hand, both groups of healthcare experts agree that their relationship with their patients is based on *mutual* rather than *one-way* trust (patient’s trust in the physician); on the other hand, they demonstrate significant deviations.

	Key findings	Doctors	MHEs
1	The patient-expert (MHE) relationship is one based on mutual trust.	Yes	Yes
2	It is non-negotiable to Know My Patient before I engage myself in a CMC session for medical/ therapeutic/ counselling purposes.	Yes	No
3	The trustworthy patient as a social construct	Yes	No
4	Considering CMC risky	Yes (misdiagnosis)	No (<i>risk-free</i>)
5	Experiencing CMC as equivalent to F2F sessions.	No (F2F superior to CMC)	Yes (“ <i>It’s almost the same</i> ”)
7	Medical data	Physical	Non-physical

Table 7.3
Key-findings Summary Table

In particular, physicians highlighted that any mode of CMC based on *subjective second-hand data* provided by their patients carries risks (i.e., *misdiagnosis*) and, therefore, it is of critical importance for them to know their patients’ trustworthiness in terms of *communicational skills*. On the contrary, MHEs not only mentioned that they experience VTS as *risk-free*, but they emphatically mentioned that they experience it as almost equivalent to F2F sessions. Finally, significant deviations were found in the nature and properties of the data that each group of healthcare professionals is looking for. In fact, physicians are keen on collecting

physical (clinical data), either through their own senses or through medical equipment, whether digital or mechanical. On the contrary, the main pool of data for the group of MHEs is *verbal* rather than physical. Although signals sent by patients' bodies (body language) can provide a useful supplementary pool of data for MHEs, it is the data transferred verbally that matter the most. It should not be forgotten that psychotherapy is also known as *talk-therapy*.

The inevitable question that arose at this stage of the analysis was:

“what could provide adequate explanations with regard to these significant deviations?”

The answer came from the data themselves. Three key-statements made by Paedia1 and Psych1 indicated that the answer should be sought on the *affordances* of the medium employed for remote communication. In particular, Psych1 mentioned that

“I could not think of even one single thing that could threat my trust-based relationship with my patients due to communicating in remote [coded as: *risk-free*]. I can see that you collect more information during face-to-face sessions, but you can also collect a lot even when you communicate in remote [coded as: *data-gap*]. In our job (psychiatrists oriented in talk-therapy), you do not have to put the stethoscope [coded as: *mechanical medicine medium*] on the patient in order to listen to his/ her lungs or heart” [coded as: *medical data (physical)*] (Psych1),

while at a later point she mentioned that

“Since one sees to the patient during Skype sessions, what difference would there be if they were here?” (Psych2)

It should be apparent -especially for researchers oriented in CMC- that Psych1 raises the *affordances* issue. What she actually mentions is that the *affordances* provided by the videoconference application are adequate for collecting the necessary (medical) data. Psych1 also mentioned that what makes her therapeutic approach different from the one of other physician specialties is that the latter should collect the necessary medical data through their own senses. Moreover, although she recognises the superiority of the face-to-face sessions, in terms of information richness, she does not believe that such a deficit (see *data-gap*) might risk

the element of trust in her relationship with her patients. Finally, at the second statement provided, she emphatically mentioned that, once the videoconference application allows the collection of both visual and sound data, VTS could be considered as equivalent to face-to-face sessions.

Similarly to Psych1, Paedia1 in her attempt to describe one of the *overuser's* properties, she mentioned that:

“[...] what puts me in an awkward position is the request for a therapeutic regimen when technology (ICT) cannot convey to me all necessary information.” (Paedia1)

In sharp contrast to Psych1, who experiences VTS as *risk-free*, Paedia1 finds herself in an “awkward position” due to the “weakness” of the medium to *afford* transferring all necessary medical data, i.e., *objective/subjective second-hand data*.

The abovementioned statements signalled the imperative need for revisiting my data through the lens of *affordances* in order to gain further understanding about why these two groups of MHEs experience the substitution of face-to-face sessions with CMC sessions in such a different way. Thirty-five events of CMC were detected within physicians’ transcripts and analysed (i.e. coded) through the lens of the medium’s *perceived affordance(s)*, the *perceived risk(s)* associated with CMCs and the properties of the *medical-data* (p. 249)

Before presenting the results of the analysis, it is worth stressing that the medium’s *affordances* were not treated as static but as dynamic ones. As it has already been stressed in Chapter 4, the drawback of the most dominant CMC theories is that they perceive *affordances* as fixed. Such static perception of a medium’s *affordances* is setting aside the potential of the user to innovate and, thus, expand the *affordances* of the medium beyond the designer’s intentions.

For instance, Phys1, with regard to digital photos as mediums for transferring data of medical interest, stated that:

“If it is just a skin condition, a photograph is the perfect medium [...] because I can have the photograph in front of me; I can see more details. I can enlarge it and see something that I would have missed with the naked eye.” (Phys1)

On the contrary, Paedia2, with regard to the same medium, stated that:

“I usually don’t like to diagnose based on a photograph (over the phone), because, you know, that is very dangerous [...] I tell them I form a different picture when I see them in person than I do from a photo; it is a completely different picture” (Paedia2)

What is made clear from the abovementioned cases is that a digital photograph itself is perceived as both a lean and a rich medium at the same time in terms of information richness due to the capacity or incapacity of the user to get the most out of the medium. Similar conclusions were drawn from the very different affordances that Paedia1 and Paedia2 recognised on videos sent via mobile phones. For instance, Paedia2 stated that:

If a parent sends me a video of a 3-month old baby coughing and asks me for a diagnosis, I'll tell them "The video is of no help to me; I want to see the child." In a clinical examination one sees more things than what comes up on a video. There are indirect signs of a disease as well as direct ones that you have to see when you examine the child.

In sharp contrast to Paedia2 perceptions with regard to the limited affordances of the video, Paedia1 praised the information-carrying capacity of videos as potential carriers of medical information. In particular she mentioned that:

So, video is a very good tool. It has been necessary to document that a child needs to have its adenoids excised; it has led me to examine the child and refer her/him to a neurologist.

To sum up, within the framework of this thesis, of the qualified term *perceived affordances* has been used instead of the term *affordances*. In other words, it was the users of the medium (i.e., physicians) who spoke about the medium’s affordances. On the contrary, they used the

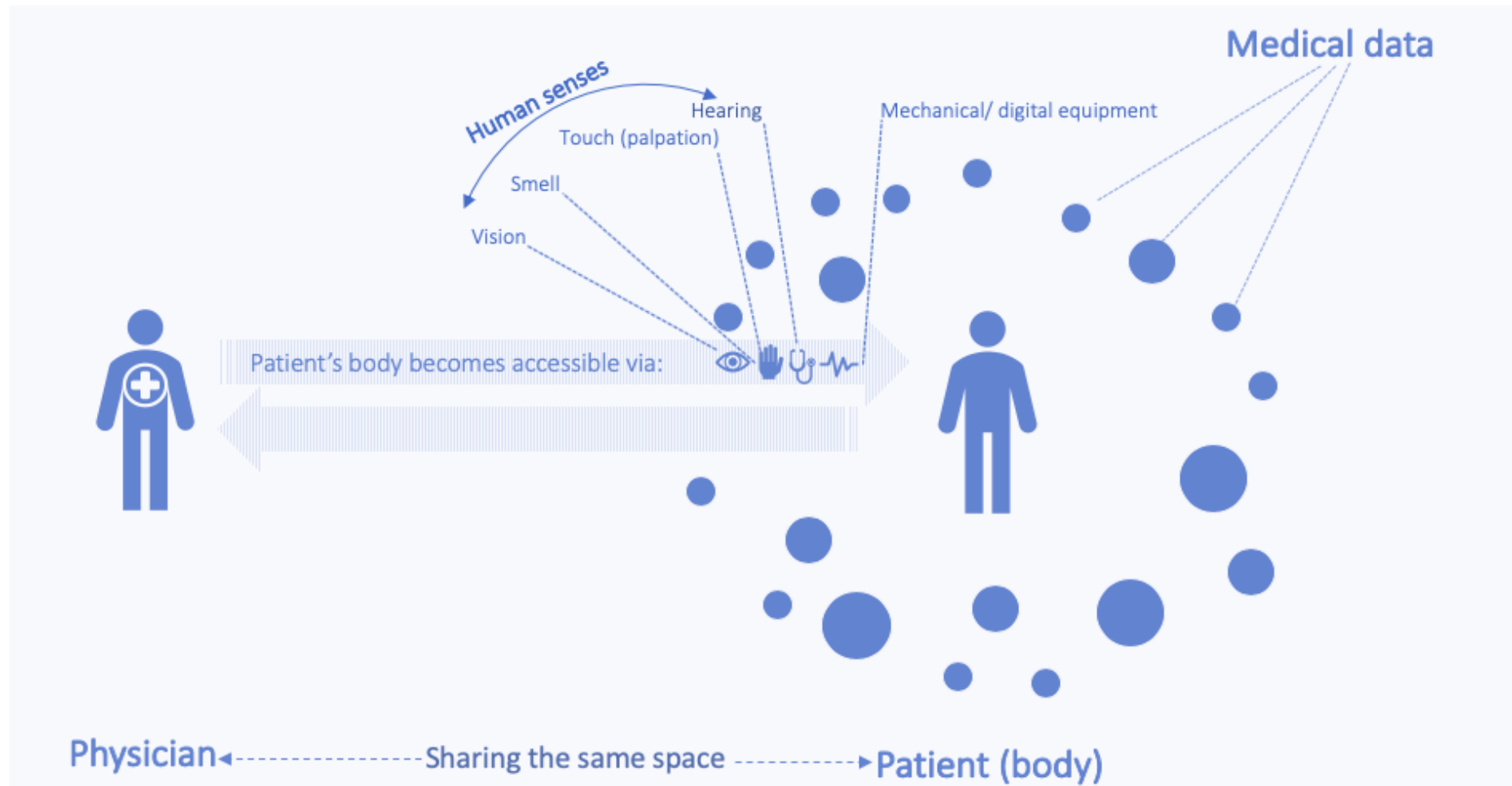
term *perceived risks* instead of *risks* in order to speak of the medium dangers identified by the users. Based on the abovementioned example, Phys1 did not share Paedia2's feeling that she would miss bits of critical data if she would decide on the basis of data provided in the photo. In other words, the intention behind the use of the *perceived risks* term demonstrates that what constitutes a risk for Phys1 does not constitute a risk for Paedia2.

7.3.2 The puzzle of *data-gaps*, *perceived affordances* and patient's communicational skills

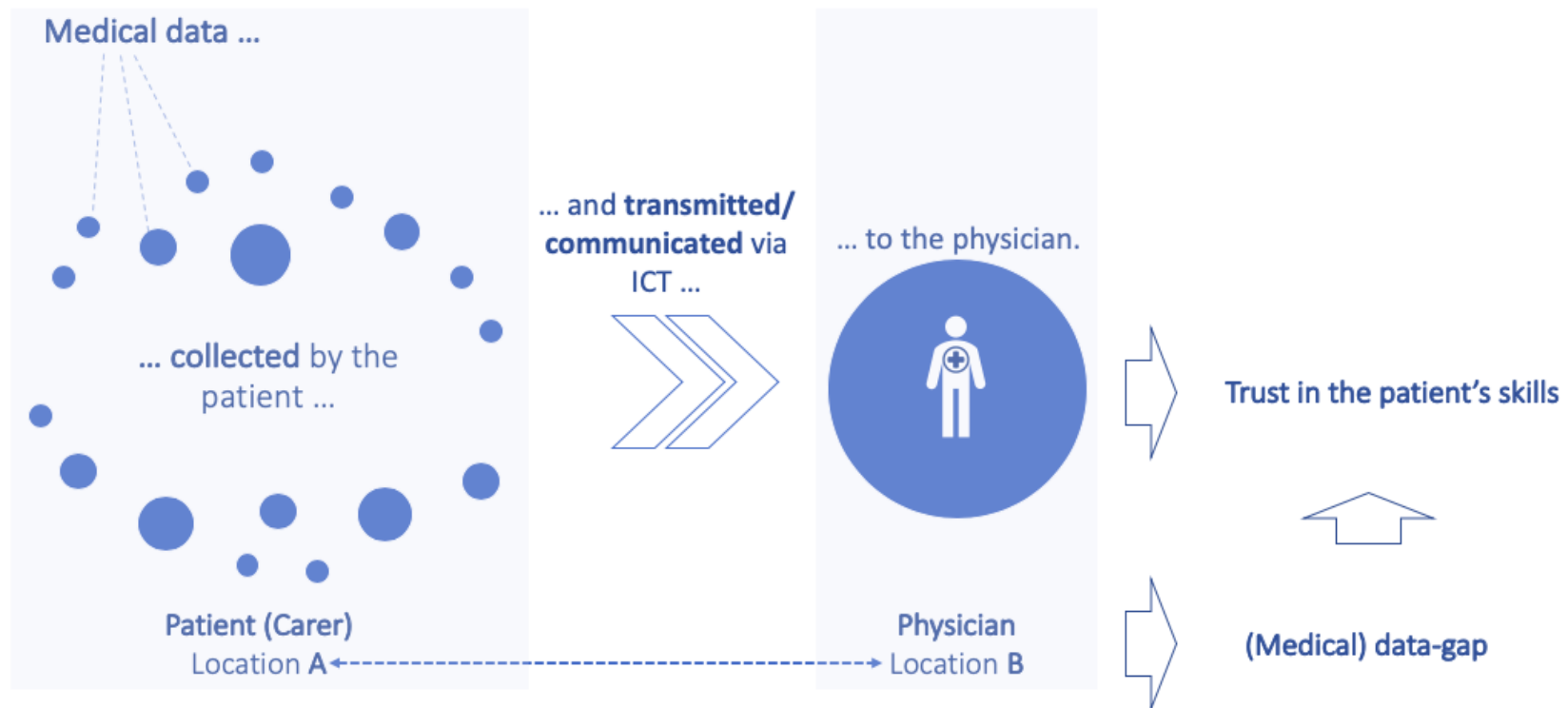
The analysis of the thirty-five cases of CMC demonstrated on page 249, confirmed that the risk of *misdiagnosis* and, therefore, the value of the TP's communicational skills, arose each time a *data-gap* was identified or implied.

As Flowchart 7.3.2a demonstrates, during a regular clinical examination the patient's body becomes accessible through the physician's senses (hands-on techniques), through specialised medical equipment (stethoscope, ultrasound-devices, etc.) or through both mediums. In other words, it is the physician who is actively involved in the medical data collection process and, therefore, who bridges the *data-gap* existing before the clinical examination. In brief, from a strict *positivist's* perspective, a traditional clinical examination should be considered, by default, the richest medium in terms of information range capacity.

In sharp contrast to a regular clinical examination, the distance between patients and doctors in the light of CMCs, brings to the fore the *data-gap issue* and, thus, the trustworthy patient's aptitudinal and communicational skills. As Flowchart 7.3.2b demonstrates, when it is not possible for physicians to have access to their patients' bodies, due to geographical constraints, they rely on patients' sensory work (see the *missing non-critical data* code under *aptitude skills* focus code) and *communication skills*. Patient's failure to collect critical medical data (sensory work) and to communicate them accurately to the physician places the risk of misdiagnosis on the latter's shoulders. In other words, during the patient-doctor CMC, it is the patient who is actively involved in the medical data collection process and -in a way- the patient's senses become the physician's senses.



Flowchart 7.3.2a
The patient-physician traditional clinical examination setting

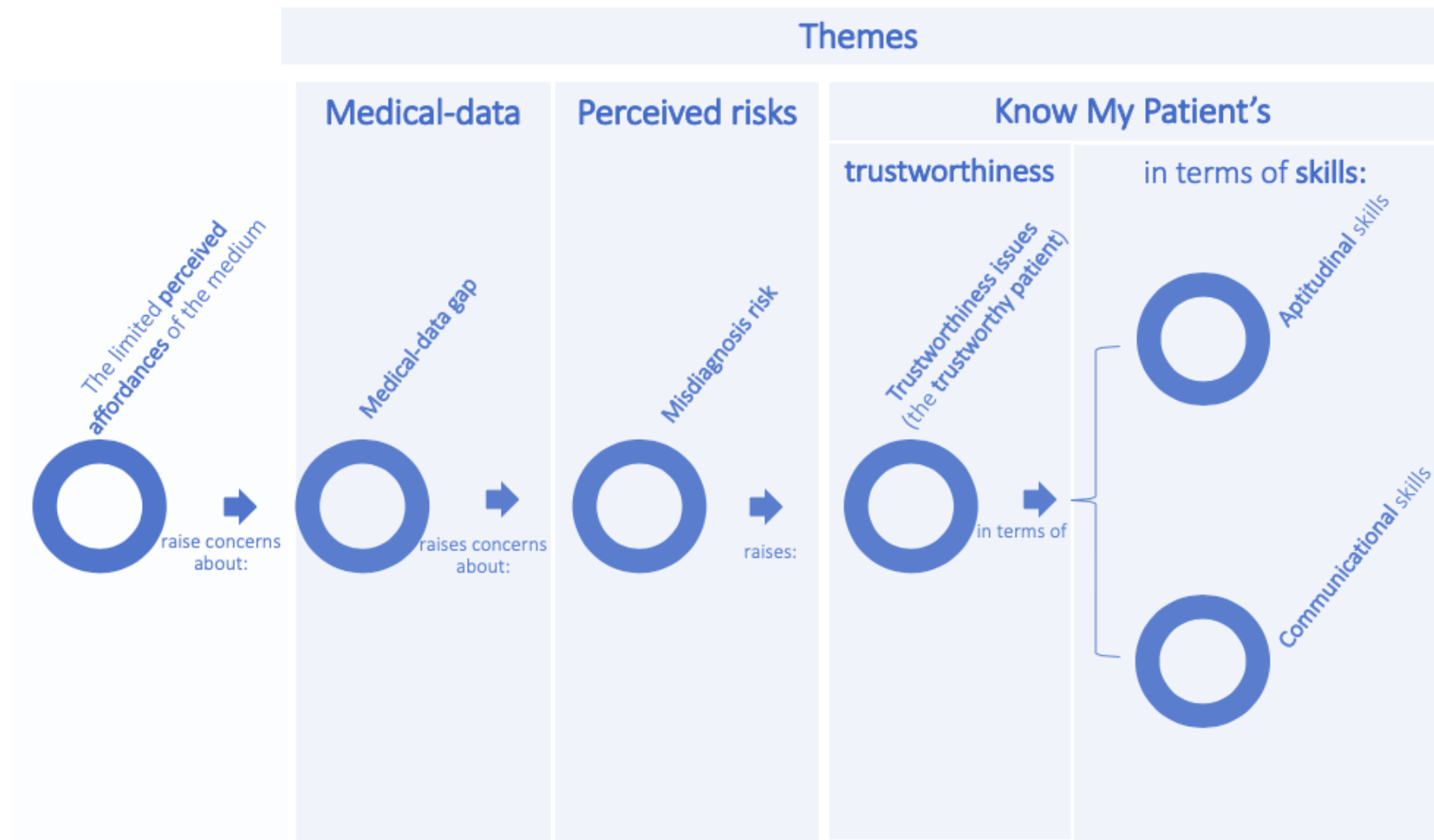


Flowchart 7.3.2b
The patient-physician CMC setting

In brief, it is important for physicians to *know their patients'* trustworthiness in terms of *communicational* and *aptitudinal* skills. Data provided by physicians indicated that patients' communicational and aptitudinal skills contribute towards minimising the misdiagnosis risk physicians face due to inaccurate, distorted, incomplete or false transfer of critical medical data.

The *perceived affordances* factor also provides adequate explanation with regard to why MHEs experience VTS (i.e., the basic ICT for substituting face-to-face sessions) as “almost” equivalent to face-to-face sessions (see the “*almost the same*” code in Chapter 5). Specifically, MHEs experience VTS as almost equivalent because videoconference is the richest technical medium in terms of information range capacity and, therefore, tends to simulate the affordances of face-to-face sessions. It should not be forgotten that, above all, videoconference applications can *provide access* to the main pool of data that attracts MHEs' attention, namely, verbal data. Nevertheless, VTS tends to simulate face-to-face sessions, but a pool of sensory and data input remains inaccessible, such as tactile data or signals/signs from the lower parts of the body. Overall, all MHEs agreed that the identified *data-gap* is not so extensive as to make them reject VTS as an alternative.

To sum up, at the one extreme, there are physicians who prefer to communicate on medical matters via ICT only with trustworthy patients to avoid the risk of misdiagnosis (see flowchart 7.3.2c) On the other extreme, there are MHEs who have no concerns about the risk of misdiagnosis and, therefore, the need for communicating with a trustworthy patient. In an attempt for generalisation, it could be supported that the less accessible the medical data of interest (i.e., the greater the data-gap), the higher the risk of misdiagnosis and, therefore, the need to work with a *trustworthy patient* in terms of *communicational* and *aptitudinal skills*. Consequently, the more accessible the medical data of interest (i.e., the narrower the data-gap), the lower the risk for misdiagnosis and, therefore, the need for a *trustworthy patient*. It seems that what makes a medical data gap major or minor is the *perceived affordances*. However, more field research should be undertaken before attempting any large-scale generalisations.



Flowchart 7.3.2c

The *data-gaps*, *perceived affordances* and *communicational skills* puzzle solved

Summary Table of key-findings

It is ***non-negotiable*** for doctors to *know their patients* before they engage themselves in a CMC session for medical purposes.

Physicians tend to reject patients' requests for CMC when the latter lack the necessary communicational and aptitudinal skills. Any mode of CMC with patients who are untrustworthy in terms of skills increases the risk of misdiagnosis.

Some physicians tend to reject patients' requests for CMC when the latter lack the necessary aptitudinal, managerial and social skills (*overusers*). This is because patients who lack such skills (*overusers*) tend to violate healthcare experts' personal and professional time.

The limited information range capacity of a medium (i.e., *perceived affordances*) in the light of a data-gap, highlights the need for a trustworthy communicator in terms of communicational and aptitudinal skills.

It is ***negotiable*** for MHEs to *know their patients* before they engage in a CMC session for therapeutic/counselling purposes.

Some MHEs tend to reject patients' requests for CMC in the light of a non-emergency matter (*manipulative patients*).

Videoconference applications afford transferring verbal data -among other types of data; this is the main pool of data for MHEs. The data-gap (data-loss) identified by each of the MHEs was not so extensive as to reject a VTS as risky or even inferior to F2F sessions.

Chapter 8

Discussion

Chapter 8 presents an extensive discussion of the emerging theory and the secondary findings that arose during the current research project. In particular, Chapter 8 begins with an integrated model of the themes thoroughly described in Chapters 6 and 7. Then follows a discussion of the emerging theory in the light of power and trust, as well as an extensive discussion of the value of the *know-my-patient* principle when distance makes CMC the only possible way of communication. Moreover, Chapter 8 provides a discussion regarding the value of healthcare experts' accessibility via ICT and physicians' trust in the patient through from the perspective of trust literature. Additionally, a note concerning the *patient's work* and *skills* in the digital-health landscape is provided, along with a discussion regarding the healthcare experts' medium selection decision. Finally, an extensive report is presented regarding implications for policy and practice. Chapter 8 ends with an account of the contribution of the current doctoral thesis to knowledge, the limitations recognised and a number of suggestions for future research.

8.1 The emerging theory

Trust is an indisputable element of the patient- healthcare expert relationship. The value of trust has been highlighted by all respondents since the very early stages of the current doctoral research project, confirming the extended relevant literature. However, subtle findings from the fields of sociology (Giddens, 1990; Beck, 1992) and sociology of telemedicine (Andreassen *et al.*, 2006; Andreassen 2011; Nettleton and Burrows, 2003; Santana *et al.*, 2010) and CMC (Riegelsberger, 2003) have offered plausible indications that trust is not expected to remain unaffected by CMC. I consider the study of trust in the patient-healthcare expert CMC setting as a research project of high theoretical and practical value, given that the digital transformation across the public health sector of EU member-states keeps gaining ground. What has been explored in the context of this thesis, is the role of trust in the patient-physician and patient-MHE CMC, via ICT products and services designed for commercial rather than medical purposes.

The current PhD thesis has demonstrated that, in the light of an identified *medical-data-gap* due to the limited *perceived affordances* of the ICT selected for CMC, *patient's trustworthiness* matter (see Flowchart 8.1.1). In more detail, it was found that

the limited perceived affordances of ICTs employed for CMC between healthcare experts and patients, a data-gap may arise, which in turn could give rise to the risk of missed, under- or misdiagnosis due to incomplete, distorted or even false data (symptoms, events, etc.) transmitted by the patient. So, it is of critical importance for healthcare experts to *know their patients'* capacities in terms of *aptitudinal* and *communicational skills* before they actively involve themselves in a CMC session for implementing a medical act. In brief, in the CMC setting, healthcare experts find themselves in a vulnerable position and, thus, they need to rely on *trustworthy patients (carers)*, i.e., on individuals who possess the necessary *aptitudinal* and *communicational skills* that will protect physicians against the risk of misdiagnosis. Similarly, when the *perceived affordances* of the ICT employed for CMC makes the critical pool of (medical) data accessible to the healthcare expert in charge, no risk and, therefore, no trust issues emerge (see Flowchart 8.1.2).

Moreover, the current PhD thesis has demonstrated how *patient's trustworthiness* in terms of *aptitudinal* and *social skills* may prevent healthcare experts from being exposed to the risk of their *professional* as well as *personal time-violation* (see the overuser). In particular, it was found that

patients who lack a set of necessary *aptitudinal* as well as *social skills*, tend to overuse the accessibility provided by the ICT to an extent that some healthcare experts feel their professional and personal time is being violated (see Flowchart 8.1.1). In brief, it is important for healthcare experts to know their patients in terms of *aptitudinal* and *social skills* before they decide to open a channel of remote communication with them.

The findings of the current thesis confirm the existing trust literature, according to which, confidence in *ability*, i.e. skills, is considered as an integral component of trust (Deutsch, 1958;

Mayer *et al.*, 1995; Thom and Campbell, 1997; Hall *et al.*, 2002; Hillen *et al.*, 1995). In more detail, the thesis confirms that individuals who find themselves in a vulnerable position tend to search for a trustworthy individual, i.e., someone who possesses the necessary skills expected so that the risk perceived may be minimised or even eliminated. What has been surprising in the abovementioned findings is that physicians, i.e., the individuals who have traditionally been considered as the powerful members of such a relationship (trustees), due to their possessing expert knowledge, are ultimately found to be in a vulnerable position and, therefore, in search of a *trustworthy patient*. In other words, it seems that in the light of CMC and due to the possibility of an adverse outcome, power is being redistributed. Such a surprising event of power re-allocation, due to the distance between the expert and the non-expert, is being discussed to a great extent in the following subsection through Giddens' perspective.

If a general conclusion could be drawn from the emerging theory, it would be that the more accessible the data, the less trust matters and, thus, the less hesitant the healthcare experts are to use ICT for communicating in remote with their patients. Consequently, if policy-makers want to get the most out of the employment of "everyday technologies" for the benefit of the patient-healthcare expert relationship without stirring trust issues up, they should be data-sensitive.

8.2 Reflections over *power* and *trust* issues in the patient-healthcare expert CMC

As it has been thoroughly demonstrated in Chapter 2, there is no trust issue in the absence of risk. Indeed, in this doctoral research project, it has been demonstrated that the risk of missed, under- or mis-diagnosis in the light of CMC raises trust issues (trust in one's patient or their carer). However, it should not be forgotten that the emergence of risk may raise power issues, too (Giddens, 1990; Luhmann, 2000; Brien, 1998). However, what has been observed in the patient-healthcare expert CMC is that the limited *perceived affordances* of the ICT seem to lead to changes in terms of power.

- **Red dashed line:** skills associated with the risk of *misdiagnosis*.
- **Green dashed line:** skills associated with the risk of *time violation (overuser)*.
- **Blue faded circles:** components of trust encountered in the literature but not in the data collected.



The emerging theory: the role of *trust in one's patient* in the **patient-physician CMC**

As it has already been mentioned, non-professionals are found to be at the “mercy” of professionals (Brien, 1998). For instance, in the patient-healthcare expert relationship, it is the possession of scientific knowledge that makes healthcare experts powerful when compared to patients. Such asymmetry in terms of scientific knowledge becomes an asymmetry in terms of power, since the patient (trustor) does not have the scientific background to monitor the physician (trustee) even if the activities of the latter were continually visible. In other words, when patients trust their healthcare experts, they are actually authorising them to access their body or psyche (*see* MHEs), either using technical (medical equipment) or physical means (palpation, etc.) in order for the best possible outcome to arise.

Nevertheless, it is common sense that the possession of knowledge without the possession of the necessary medical data is like a processor with no data to process. In other words, how powerful might a healthcare expert be when he possesses the scientific knowledge but not the necessary medical data (symptoms, etc.) to proceed and reach a decision? For instance, in this thesis it has been observed that when patients’ bodies become inaccessible, physicians find themselves vulnerable, since they have to rely on and trust their patients’ aptitudinal and communicational skills. In this sense, I hold the view that professionals lose part of their power capacity because they become dependent on non-experts’ perception and skills. To sum up, in the light of CMC, physicians, i.e., the powerful members of this trust-based relationship, are found to be losing power due to restricted or, even, no access to critical medical data through their own senses.

At first glance, the emerging theory presented seems to confirm Giddens’ (1990) view that “trust is related to absence in *time* and *space*”, as well as that there would be “no need to trust anyone whose activities were continually visible” (p. 49). Data analysis indicated that the need for a *trustworthy patient* with *aptitudinal* and *communicational skills*, emerged in the light of distance between patients and physicians, or what Giddens defines as *space*. According to Giddens, there would be no need for a *trustworthy patient* if their bodies were accessible either through the human senses or medical technologies (wearables, etc.) that would be perceived as trustworthy extensions of human senses. As Diab1 highlighted with regard to *on-line data* transferred via wearable accessories, such as smart watches:

“the ideal scenario would be to receive data on your PC directly from the mobile device (i.e., smart-watch) without any intermediary intervention [...]; I used to know a colleague in New York, a resident, whose son suffered from diabetes. My colleague used to monitor his son’s blood sugar levels from New York, while his son was playing football in San Francisco.” (Diab1)

What Diab1 actually highlighted was the capacity of wearable technologies to provide real-time access (*see* Giddens’ *time* component) to measurable medical data located remotely, the quality of which could not be distorted by a patient’s unreliable aptitudinal and communicational skills. The emerging theory presented in the current thesis confirms Giddens’ view, i.e., that trust issues emerge in a setting where it is not possible for human senses to be utilised for monitoring due to temporal and spatial constraints. At this point it should be noted that Giddens’ view about how the elements of *space*, *time* and *human senses* are associated with *trust*, could provide adequate explanations why the current thesis is among the very first studies that speak of a *trustworthy patient*. In other words, it is not a coincidence that the social construction of the *trustworthy patient* emerged in remote communication where the senses of touch or olfaction are in a dormant state.

Additionally, the emerging theory defended in the current thesis appears to confirm Giddens’ view that “the prime condition of requirements for trust is not lack of power but lack of full information” (Giddens, 1990:49). Indeed, data analysis indicated that it was the medical-data-gap identified, i.e. what Giddens defines as “lack of full information”, that led to the need for a patient who would be able to identify and accurately report their actual events or symptoms. In other words, though it was still physicians who possessed the power of expert knowledge, they found themselves in a vulnerable position because it was not possible to collect critical medical-data using their own senses. Instead, it has been a case of the non-experts, i.e., patients and carers, who were expected to identify, collect and, finally, communicate necessary medical information accurately. On the contrary, the *perceived affordances* of the means employed by the MHEs for CMC provided sufficient accessibility to the critical pool of data they were keen to collect, i.e., verbal data. To Giddens’ mind (1990), MHEs reported no “lack of full information”, which, in my interpretation and data-analysis explains why MHEs

raised no *trust in one's patient* issues. Overall, I would attribute the vulnerability experienced by physicians to the substitution of human senses by means of lower *perceived information richness capacity*.

However, the emerging theory challenges Giddens' (1990) epistemology over human senses, according to which, "sense data could never provide a wholly secure base for knowledge claims" (p. 49), citing the early representatives of the Enlightenment, who used to claim that "such evidence is always, in principle, suspect" (p. 49). Though the epistemological view held within the current thesis is that our senses are the means through which we are experiencing the external world, it is also recognised that they may lead to erroneous results. Conventional technologies, such as the stethoscope or the microscope, would not have been developed if we considered our senses as the most reliable means. However, the emerging theory demonstrates that lack of physical proximity seems to be responsible for physicians' power leak, due to what Giddens refers to as "lack of full information". That is why the interest emerging over artefacts described in Chapter 3, such as *data sculptures*, *data physicalisations* or *physical visualisations* (Lupton, 2017), should not be considered as an accidental event. As it has been thoroughly explained under 3.4, the rationale behind the design of such artefacts is to facilitate knowledge of physical data beyond the sense of vision. Their main property is that they invite haptic sensations, such as texture, stiffness or even temperature, and render them into 3D forms (Lupton, 2017). My interpretation also seems to confirm research work which has supported that "the risk of devaluing the experiential, haptic and affective knowledge of both apprentices and practitioners" (Mort and Smith, 2009:215) is always present in the absence of physical proximity. Moreover, Mort and Smith (2009), among others (Mort *et al.* 2003, Lupton 2013), have supported that incomplete medical data (see Medical-data-gap) may arouse a sense of uncertainty in healthcare experts.

The discussion of the emerging theory through Giddens' 'lens' provides subtle indications that the closer the *perceived affordances* of the means employed for CMC to the perceived affordances of the human senses, the narrower the *perceived medical-data-gap* and, therefore, so the less the exposure of the healthcare expert to the *perceived risk of misdiagnosis*. Experience drawn from the patient-MHE CMC has demonstrated that the minimisation of medical-data loss due to the high information richness capacity of the ICT, will

not raise trust issues in the patient-healthcare expert relationship. I would expect that upon achieving to produce ICTs that tend to simulate human senses' affordances healthcare experts' interest will shift from trust in one's patient's skills to trust in the medium (i.e., in the technologies used). The development of such technologies could prevent the classification of some patients as *non-trustworthy* because they lack the necessary skills and, therefore, prevent the emergence of a digital divide phenomenon in the e-health field. Moreover, I would expect that such a shift could help healthcare experts feel less depended on patients' skills and, therefore, less vulnerable. In my interpretation, the *perceived medical data-gap*, as a product of the medium's *perceived limited affordances*, disempowers healthcare experts by exposing them to the risk of missed-, under or- mis-diagnosis, since they have to rely on the non-experts' aptitudinal and communicational skills. In a way, it seems that, in the light of distance, patients' senses become the extension of the healthcare experts' senses. However, no safe generalisations can be extracted at this stage and, therefore, further research is recommended.

8.3 The value of *knowing one's patient* in the CMC setting

Personalised medicine has been a high priority for the European Commission and its agenda given the digital transformation of public health systems. The policy makers of the European Commission define *personalised medicine* as "an emerging approach that uses data generated by new technologies to better understand the characteristics of an individual and deliver the right care to the right person at the right time" (European Commission, 2018:7). However, limited, yet emerging, research works have highlighted that *knowing the patient* as a *whole person* (Finch *et al.*, 2008) and not just as a cluster of genomic or medical data (molecular profiling, diagnostic imaging, etc.), is of critical importance for designing an effective telemedicine platform (Finch *et al.*, 2008; Mort *et al.*, 2003). In the first place, the KMP theme, as a product of the current doctoral thesis, sheds light to the value of *knowing the patient (carer)* in the CMC setting. Moreover, it extends our knowledge by providing evidence grounded on robust data that it is of critical importance -particularly for physicians- to be aware of their patients' skillsets and personal profiles. It is concluded that the medical-data-gap identified and the risks resulting from it might be minimised only if healthcare experts operating in remote are aware of their patients' trustworthiness in terms of *communicational*, *aptitudinal* or, even, *social* skills.

8.3.1 The value of KMP/C: a *medical-data* perspective

According to the first pillar of the *know my patient (carer)* theme, it is truly importance for all physicians to be aware of their patients' medical history (*see regularity* code) before implementing any medical act in remote. According to Huffman (1972), the medical record "must contain sufficient data to identify the patient, support the diagnosis or reason for attendance at the health care facility, justify the treatment and accurately document the results of that treatment" (Huffman, 1972). It is common sense that to know a patient's medical history contributes towards "the continuing care of the patient when they require health care in the future" (WHO, 2006), regardless of the setting, i.e., CMC or face-to-face. The value of *knowing one's patient* in terms of psychopathology has also been stressed by MHEs, too, although analysis demonstrated that they tend to focus on totally different elements when compared to physicians.

In our era, when *remote doctors and absent patients* (Mort et al., 2003) meet in the *empty space* (Giddens, 1990) keeping vital human senses in a dormant status, the value of accurate medical data becomes even more critical. It should not be forgotten that ambitious objectives set by the European Commission, such as the one of *patients' empowerment* or the establishment of *patient-centred* and *personalised medicine* services, rely on the assumption that detailed, as well as accurate medical data, become available. To that extent, the aspect of *regularity* as a category of the KMP theme confirms existing literature. As demonstrated under 8.2.3, an even closer reading of the *personalised medicine* definition provided by the European Commission (2018), reveals that *knowing the patient* solely in terms of medical data is not adequate in itself/*per se*.

8.3.2 The value of KMP/C: a *skills* perspective

The European Commission (2018) expects that *personalised medicine* should focus on "the characteristics of the individual" (p.7) so as to deliver tailor-made rather than custom-made care at the right time. As Wong-Rieger (2012) denoted, healthcare experts should be aware of whether the patient possesses the *abilities* required "to interpret the choices and instructions formulated by the health care provider" and to "take responsibility for their health into consideration when involving the patient" (p.8) in the decision-making progress. Similar to Wong-Rieger (2012), Mort *et al.* (2003) stressed the importance of *knowing the patient* beyond

medical data and in terms of psychosocial state, levels of anxiety, fears and concerns, as well as their family status or family life. It was also Shea and Effken (2008) who reported that it is important for nurses operating in remote to be aware of both their patients' and their carers' "hands-on" skills.

The second and third pillar of the KMP theme regarding the value of a *patient's trustworthiness*, in terms of skills and personal qualities, not only confirms the existing literature review about the value of *knowing the patient* in advance of the patient-physician CMC sessions (Tanner *et al.*, 1993; Radwin, 1996; Mort *et al.*, 2003; Langley and Klopper, 2005; Andreassen *et al.*, 2006; Finch *et al.*, 2008; Wong-Rieger, 2012, European Commission, 2018), but also extends it. In the first place, the emerging theory confirms findings that have highlighted the value of effective communication in the traditional patient-healthcare expert trust-based relationship (Shea and Effken, 2008; Thom and Campbell, 1997; Ong *et al.*, 1995). Moreover, it confirms limited findings from the field of e-health that underline the value of communicational skills in the light of remote communication between patients and healthcare experts (Curtis, 1989, Roing *et al.*, 2013; Derkx *et al.*, 2009). Nevertheless, to the best of my knowledge, the current thesis is the first to mention the key-role of patients' communicational skills towards the achievement of an efficient medical encounter using ICT. Moreover, this doctoral thesis is among the very first research works in the field that associates *patient's trustworthiness* with their communicational skills, extending the work of Thom *et al.* (2011), who found that it is invaluable for doctors, in terms of trust in their patients, to deal with patients who provide *accurate and complete information* and are capable of (a) providing all necessary medical information; (b) accurately reporting symptoms; (c) providing reliable information, while (d) informing the doctor about any major change in terms of their health condition. My findings are consistent with these views, in that the *trustworthy patient* is an individual who demonstrates, *inter alia*, effective communication skills, such as accurately transferring reliable data. My findings also echo those by Roing *et al.* (2013), in placing emphasis on the patient's speaking skills, reporting that communication on the phone becomes challenging, particularly in cases when the patient is not a native Swedish speaker. Both speaking skills coded as *uninterrupted flow in communication* and accurate data-transfer were dominant/prevaling factors in my interviews.

The KMP theme also revealed that it is of critical importance for doctors to be aware of their patients' aptitudinal skills in addition to their communicational ones. As it has already been demonstrated, both aptitudinal and communicational skills of a patient seem to play a decisive role in a healthcare experts' decision to open a CMC channel with their patients or not. Skills relevant to the ones defined as aptitudinal in the current thesis have been reported by Oudshoorn (2008), as well as by Lupton and Maslen (2017). In this thesis patients' skills to recognise their symptoms (Oudshoorn, 2008), as well as patients' *sensory work* (Lupton and Maslen, 2017) have been coded as *aptitudinal*. Consequently, it could be supported that findings reported in the current thesis not only confirm existing, albeit limited, findings, but also expand existing knowledge.

8.3.3 The value of the KMP/C: a *personal qualities* perspective

Moreover, the extensive KMP theme revealed that it is important for physicians to be aware of their patients as personalities, besides their skillsets. For example, physicians demonstrated a special interest in their patients' stress levels (coded as *fearful*, *overanxious*), propensity to trust other people (coded as *skeptical*) or even attitude towards serious health (see *Laid-back* patients). The codes reported confirm research work by Finch et al. (2008) in the field of telehealth, which highlighted the need to take into consideration non-medical information, as well, in regard to patients' psychosocial state, levels of anxiety, fears and concerns, including their family status or family life.

Although findings reported both in the current thesis and by the relevant literature review demonstrate that it is of high importance for the healthcare experts who operate in remote to be aware of their patients' medical history, skills and personality in regard to CMC, there have also been voices challenging this principle. As demonstrated in Chapter 7, although it is important for MHEs to know who their patients are prior to their CMC sessions, this is not considered to be an unconditional prerequisite. Similar findings have been reported by Tate et al. (2001) as well as Dunbar et al. (2003) in that, although no knowledge between the healthcare expert and the patient existed prior to their remote communication, e-mails had a positive impact in terms of a patient's adherence to therapy.

However, I would add that sending multiple, short, daily text-messages in order to remind, educate, encourage adherence and provide information regarding side effects is not the same as providing live personalised guidance in response to an unexpected or expected event or symptom. The former case has to do with customised text-messages sent to a group of patients with similar therapeutic goals undergoing established treatment regimes, while the latter case concerns feedback responding to an individual case. For both patients and healthcare experts, such modes of remote communication demand further and careful consideration in terms of risk and effectiveness. As Car and Sheikh (2004) suggested: “the strong drive to incorporate e-mail consultations into routine clinical practice should proceed on the basis of secure evidence.” (p. 435).

To sum up, the KMP theme presented, confirms research work about the necessity for healthcare experts to *know their patients* (Tanner *et al.*, 1993; Radwin, 1996; Nilson *et al.*, 2008; Zolnierrek, 2014; Langley and Kloppe, 2005). Moreover, findings from the emerging field of e-health about the value of the principle ‘*knowing one’s patients*’ beyond their medical or biological-data profile, before implementing any medical act in remote, are also confirmed. The current doctoral thesis expands existing knowledge by providing adequate indications that *knowing the patient (carer)* in terms of skills and personality (coded as personal qualities) could be proved an effective strategy for hedging risks associated with CMC, such as the ones of missed, under- or mis-diagnosis, or the one of professional and personal time violation. However, the limited volume of research work that challenges the value of prior knowledge between patients and healthcare experts (Tate *et al.*, 2001; Dunbar *et al.*, 2003) prior to their CMC sessions, does not leave enough margin for generalisations. Consequently, further research should be implemented before mid- or macro- level theories become publishable.

8.4 Reflections over the *accessible* healthcare expert

As already demonstrated, patients who lack both aptitudinal and social skills turn to ICT to such an unreasonable extent, that they cause, feelings of irritation in healthcare experts. However, data emerging from the group of MHEs provided subtle, yet plausible, indications that the accessibility to the healthcare expert provided by ICTs has the potential of contributing towards building, maintaining or even empowering trust (see 6.4). It is reminded that all MHEs

supported that *being accessible* to their patients via ICT at difficult times (coded as *times of crisis*), is an alternative way of “*being there, being present, being supportive*” for and to them, which is perceived by patients as a tangible form of care (benevolence), i.e., an integral component of trust.

This research work confirms a limited volume of research work speaking of the positive contribution of healthcare experts’ accessibility to their trust-based relationship with their patients, via e-mail and texting services, in particular. My own findings confirm those of Bjerke *et al.* (2008), who had found that texting services (SMS) offered patients struggling with substance abuse and psychiatric disorders a sense of proximity to the MHE, even though the MHE was not physically present. Such ‘presence’, defined and coded as ‘perceived presence’ (p. 199) by Bjerke *et al.* (2008), has been explicitly described by one of the participants as ‘a permanently outstretched hand from a person who cares’ (p. 199). Delbanco *et al.*, (2004) reported that e-mail offers the opportunity for both “doctors and patients to move closer together, and trust grows strikingly (Delbanco *et al.*, 2004:1707). Similar indications were offered by Yager (2001), who reported that patients suffering from *anorexia nervosa* stressed that e-mails offered them a sense of being in closer touch with and taken more care of by the healthcare expert. Finally, positive contribution of ICT in favour of trust in the patient-healthcare expert relationship has also been reported by Nilsson *et al.* (2010). Their results revealed that nurses felt the *increased accessibility* offered by electronic messaging programs, via computers and mobile phones, to nursing care personnel, offers the opportunity for developing a more trusting relationship. In other words, tele-home care offers patients a chance to access district nurses at any time, which may lead to a solid trust-based relationship. The two district nurses of Nilsson *et al.* (2010) also underlined the importance of *knowing the patient* before implementing the tele-care program, as necessary for creating the conditions necessary for individual care.

Furthermore, the current doctoral thesis confirms findings reported by Shea and Effken (2008) from the field of tele-nursing and telecare, which highlighted that “trust is enhanced when patients truly believe that their nurse wants them to contact him or her whenever they have a concern no matter how small it may seem” (p. 139). They concluded that both synchronous and asynchronous ICT may have a positive effect on trust and its three characteristics of *ability*,

integrity and *benevolence*. However, as the current research thesis revealed, the *overuse* of ICT concerning issues that are perceived by healthcare experts as minor may make the latter feel their professional and personal time is being violated. That sense may not only make healthcare experts speak of *non-trustworthy patients*, but also discourage them from using any mode of CMC. However, no safe generalisation could be made at this point due to the limited volume of research work. It is suggested that further research should be undertaken into how healthcare experts experience being accessible to their patients via either synchronous or asynchronous means of communication.

At this point it is important to make a critical note of the abovementioned findings in regard to *technology affordances*. The contribution of physical presence, and touch, in particular, as a channel to *afford* empathy and, ultimately, to build trust, has been mentioned by scholars of different disciplines. For instance, Shea and Effken (2008), as well as Nilsson *et al.* (2010), from the field of telecare and tele-nursing, have reported that physical touch in the form of a hand on a shoulder, eye-contact, touch, voice tone or facial expressions, is irreplaceable for trust-building. Similar views are coming from the field of management and virtual organisations. According to Handy (1995) touch in the form of face-to-face interactions, such as work and play, promotes trust building among virtual-team-members of virtual organisations (i.e., *touch*). In brief, there are subtle indications coming from more than a single discipline that “trust needs touch” (Handy, 1995: _). However, the current PhD thesis, among other research papers, not only challenged the fact that physical proximity may be the only way for maintaining or even building trust, but it also provided subtle indications that the richness in terms of information capacity afforded by the medium does not really matter. For instance, Bjerke *et al.* (2008), Delbanco *et al.* (2004) as well as Nilsson *et al.* (2010) found that accessibility to the healthcare expert provided by a variety of text-based services (SMS, e-mail, electronic messaging platforms, etc.) may well work in favour of trust. Similar to the abovementioned findings, the MHEs interviewed for the purposes of the current thesis, made reference to a broad variety of ICTs (SMS, emails, phone-calls and video-conference sessions) both in terms of synchronicity and affordances.

As Psych1 underlined:

“If the patient feels that you are available in any way, be it Facebook, pigeon mail or anything else, then they feel comfortable. They feel secure, they feel much better.”

At first glance, and from a positivistic CMC perspective, it is obvious that Psych1 associated accessibility to media of different capacities in terms of *technology affordances*. It is reminded that according to the rather positivistic perspective of the *information richness* as well as the *social presence theory*, ICTs supporting texting are considered as the leanest media in terms of information richness capacity, due to their weakness to afford richer data, such as pictures, videos or human senses, namely touch and smell. Overall, it seems that, regardless of the medium's affordances, ICTs have the potential to build, maintain or even empower trust, which lies at the core of the patient-healthcare expert relationship.

Still, generalisations should be avoided at this stage, not only due to the limited number of studies referred to, but also due to the lack of awareness about the mechanics of trust-building via CMC. It is suggested that further research should be undertaken introducing properties, theories and terminology from the field of CMC.

8.5 The physicians' trust in the patient through the 'lens' of trust literature

The emerging theory thoroughly described in Chapter 7 demonstrated that the patient-physician CMC raises risk issues (misdiagnosis) due to the limited capacity of the ICT to make the necessary medical information accessible. Such a limitation exposes physicians to the risk of missed, under or mis-diagnosis and, hence, places them in a state of vulnerability. Physicians expect that the risk identified is minimised if they trust patients' whose aptitudinal and communicational work they assess as reliable. In other words, the *trustworthy patient (carer)* is a skilful individual. The rationale behind the emergence of the social construction called *trustworthy patient (carer)* confirms trust literature, according to which, confidence in ability, i.e. skills, is considered an integral component of trust (Deutsch, 1958; Mayer *et al.*, 1995; Thom and Campbell, 1997; Hall *et al.*, 2002; Hillen *et al.*, 2011).

In other words, physicians seem to share the view held by Lewis and Wegert (1985) with regard to *cognition-based trust*, according to which:

‘we choose whom we will trust in which respects and under what circumstances, and we base the choice on what we take to be ‘good reasons’ constituting evidence of trustworthiness’ (p. 970)

As it thoroughly described under 8.3, it is the multifaceted *knowledge of the patient*, both in terms of skills and personality, that let physicians judge whether a patient or a carer is trustworthy or not. It is reminded that the value of knowing ‘who is who’, particularly in the case of relationships where trust is considered necessary for them to be functional, has also been supported by Lewicki and Bunker (1995). If we approach patient-doctor remote communication through the lens of Lewicki and Bunker’s (1995) *knowledge-based trust*, we should come to the conclusion that the more doctors know their patients, the deeper they can trust what the patient does, because they can accurately predict how patients will respond, even in the context of remote communication. It was Lewicki and Bunker (1995) who had underlined the importance of knowing the other party through continuous interaction and communication, if a trust-based relationship based on information, i.e. prior knowledge, is to be achieved. The value of *knowledge-based trust* also comes from a rather outdated, yet relevant paper, supporting that “[o]f course, the more familiar a physician is with the caller, the more certain he or she will be about interpreting the caller’s presentation of the problem and deciding on the subsequent management” (Curtis, 1989:123).

Moreover, the value of knowledge-based trust, i.e. knowing “who is who” prior to CMC sessions via ICT between members located at a distance, has also been mentioned by studies from the field of CMCs, virtual teams and teleworking. Zheng *et al.* (2002) as well as Rocco (1998), from the field of virtual and teleworking teams, found that team-members who had known each other prior to their remote collaboration usually establish higher levels of trust, in sharp contrast to those who had not, and, thus, tended to underperform. Similarly, in the early 90’s, Nohria and Eccles (1992) reported that the ‘effectiveness of electronic networks will depend on an underlying network of social relationships based on face-to-face relationships’ (Nohria and Eccles, 1992, as cited by Rocco, 1998:496).

Moreover, the value of knowing our communication partner in terms of trustworthiness prior to CMC sessions has been found to play a critical role in the user’s medium selection (Lo and Lie, 2008). It was Lo and Lie (2008) who mentioned that

“if significant distrust exists between the partners, the tolerance level of perceived risk during the interaction will be lower, and the communicator will likely opt for a communication channel with a higher degree of information richness that transmits more information, in order to lower the degree of uncertainty inherent in the interaction” (p. 147)

As demonstrated in Chapter 6, doctors who challenge their *patients’ trustworthiness* in terms of the latter’s ability to accurately communicate *subjective, second-hand data*, encourage these patients to visit the nearest hospital in order to minimise the possibility of misdiagnosis when a clinical examination (either at the doctor’s or the patient’s premises) is not feasible (see Flowchart 7.1.2). In other words, when patients lack the necessary communicational skills, they are not considered trustworthy from a skills perspective and are, therefore, inappropriate candidates for remote communication. That finding seems to verify Rocco’s (1998) view, from the field of CMC, supporting that electronic communication may, ultimately, prove inappropriate for supporting teamwork, particularly ‘when trustworthiness is a prerequisite for action [...]’ (p. 501). Additionally, Rocco had similarly stressed the value of communication in cultivating trusting relationships, which seems to be confirmed by my research findings, too.

It is not only the definition of *cognitive* (Lewis and Wegert, 1985) or *knowledge-based trust* (Lewicki and Bunker, 1995) that defines physicians’ trust in their patients in the setting of CMC. As demonstrated, physicians’ decision of opening a channel of remote communication between them and their patients or not, is the product of calculations based on data collected at an earlier time about their patients’ skills, as well as the product of risk-assessments in cases where patients do not fulfil their expectations. In that sense, physicians’ trust in their patients could be described by the definition of *calculus trust* (Lewicki and Bunker, 1995) based on a ‘costs- benefit’ assessment in the light of a positive or negative scenario.

To sum up, a physician’s *trust in the patient* seems to confirm definitions of trust found in traditional trust literature, such as those of *knowledge* and *cognitive-based trust*, as well as those of *calculus* and *interpersonal trust, as well*. Overall, the *trustworthy patient (carer)* is a skilful individual, capable of responding to the challenges of sensory and communicational work required in the CMC setting. In other words, the core of a physician’s trust in the patient is not what Sako (1998) defines as *goodwill trust*, which encompasses the absence of

opportunistic behaviour or the will to over perform. Instead, the core of a doctor's trust in the patient is better described by what Sako (1998) defines as *competence trust*, i.e., trust based on the trustees' skills and abilities.

8.6 A note over the *patient's work and skills* in the digital-health landscape

“work does not disappear with technological aid. Rather, it is displaced sometimes onto the machine, as often onto workers” (Illitch, 1981, cited in Oudshoorn, 2008, p. 272).

As it has been extensively discussed, the *trustworthy patient (carer)* is a multi-skilled individual. The emerging theory developed within the framework of the current thesis demonstrates that individuals who do not possess the necessary communicational, aptitudinal and social skills are finally considered as inappropriate for CMC. However, the numerical supremacy of the skills-associated codes in the KMP theme, implies the existence of work that has to be done either on behalf of the patients or carers in charge. In particular, the case of the patient-healthcare expert CMC explored in the current thesis showed that in the absence of a skilled patient (carer), remote communication not only can't be functional, but it can also be risky. In other words, a skilled patient (carer) seems to be a necessary component for the patient-physician CMC mechanism to work. As it is being demonstrated below, the current thesis confirms Illitch's (1981) thesis that in the light of technological aid, work does not disappear but instead “it is displaced sometimes onto the machine, as often onto workers” (cited in Oudshoorn, 2008, p. 272). In particular, what is being supported in the following paragraphs is that the integration of ICTs in health services, adds extra work load not only to healthcare experts but also to patients i.e. the non-experts.

It is common knowledge that revolutionary technologies developed in the current years have displaced much of the work that used to be implemented by healthcare staff onto smart devices. For example, technologies such as the *internet of things* (IoT) that have been merged into light-weight everyday technologies such as mobile phones or smart watches, have the potential to make detailed tracking of key health ratios and medical data which in turn it is possible to be monitored on-line by the healthcare experts themselves. As Paedia1 mentioned,

“...the *****watch will really help much with asthmatic children, because its sensors measure and record oxygen saturation” (Paedia1)

In other words, the advent of the IoT it did displace work that used to be performed by healthcare professionals onto wearable devices verifying Illitch's (1981) thesis.

However, the current doctoral thesis along with Oudshoorn's (2008) research work, demonstrates that the integration of advanced ICTs in the field of telemedicine and telecare, does not necessarily mean that control over medical care is being taken away from physicians and other health care providers. For instance, experience drawn from Paedia1 and Paedia3 provided evidence that dealing in remote with *laid-back parents* in the role of informal carer, it is possible to add extra work to their daily professional routine due to lacking basic aptitudinal skills. As Paedia1 stressed, *laid-back patients* oblige her to make an additional number of follow-up phone calls to the child's parents, since she does not consider them *trustworthy*. In other words, it is the parents' lack of risk-assessment skills that obliges her to spend more time making phone calls than she would normally do. Moreover, as it has been extensively discussed, for healthcare experts being accessible to patients and carers who lack basic aptitudinal, managerial and social skills, it is possible to set at risk their professional and personal time. In other words, patients who are not capable of implementing basic daily tasks associated with their illness it is possible to burden their healthcare experts in charge with extra work.

However, what dominated in the current thesis was not healthcare experts' extra work but instead *patient's (carers) work*. The lack of proximity makes it impossible for physicians to make use of their senses for performing basic clinical work such as the one of palpitation and so the sensory work is displaced onto patients (carers). In the CMC setting between patients and physicians, patients it is expected to perform *sensory work* (Lupton and Maslen, 2017) i.e. to make use of their own senses in order to scan their own bodies with caution so that not to miss easily-observable symptoms. Moreover, it is expected to be risk-aware, think critically as well as to easily learn tips and hints associated with the management of their illness. However, the numerical supremacy of the codes referring to the *trustworthy patients'* communicational skills, reveals the high expectations that physicians have from their patients' communicational performance and thus work. Patients it is expected to transfer reliable subjective second-hand data with accuracy, to communicate high-quality second-hand objective data with via ICT and generally to be able to transfer either in a verbal or a written form symptoms and events. As it

has been demonstrated, in addition to the aptitudinal and communicational work, the *trustworthy patient* it is expected to perform managerial as well as organisational work.

At this point it should be highlighted that the concept of *patient work* is not a term coined by e-health scholars in order to reflect the work assigned to patients due to the pompous advent of ICTs in the health domain. As Corbin and Strauss' (1988) work reveals, patients had work to do associated with their health issues a long time ago before the rapid integration of ICTs in the field of healthcare. Though I share Rogers et al.'s (2011) position that "aspects of patients use of telehealth and telecare can be seen as professionally delegated work" (p. 1077), I would urge that further research should be done so that to identify to what extent and in what terms ICTs are responsible for the work assigned to the *future patient*. For example, experience drawn from the group of MHEs did not provide any indication that therapy sessions via videoconference devices or even regular phone-calls assigned extra work to the patients compared to the one assigned during the regular face-to-face sessions. Although there are plausible indications that the "diagnostic socio-technical work" (Rogers et al., 2011:1077) that used to be part of home-care professional nurses' and physicians' job responsibilities now are displaced onto patients, yet no safe generalisations should be made.

8.7 The medium selection decision: the healthcare experts' case

The current doctoral thesis is the first research work from the broader field of telemedicine sociology studies that borrows the key theoretical lens of *affordances* from the field of CMC studies, in order to shed light to the unexplored role of trust in the patient-healthcare expert CMC. Though it was not in my initial methodological planning to do so, drawing theoretical knowledge and experience the discipline of CMC studies, not only unblocked the analysis but also it took it even further at a stage when the emerging findings were found to be contradictory. It is reminded the stage where MHEs not only challenged the existence of the *trustworthy patient*, but also defined their CMC with their patients as risk-free, totally challenging the physicians' perspectives. Revisiting my data through the lens of *affordances*, not only took the analysis further but also gave space for a theory to start taking shape. At this point it is worth to mention that though the current interdisciplinary PhD thesis belongs more to the field of telemedicine sociology studies, it did produce findings which are relevant to CMC theorists' research interests.

In the first place, the current thesis challenged the established idea that CMC is by default interwoven with the element of *risk*. It is reminded that such a thesis has been supported not only by CMC scholars (Lee and Watson-Manheim, 2014; Lee et al., 2007) but also by influential sociologists (Giddens, 1990; Beck, 2003; Riegelsberger, 2003). It is a fact that the patient-physician CMC was found to be interwoven with the *perceived risk* of misdiagnosis i.e. what Lee et al. (2007) have defined as *communication failure*. In particular, the incapacity of the daily ICTs being studied in the current thesis to simulate the human senses' *affordances*, was found to raise *risk* and thus *trust* issues. However, experience drawn from the MHEs' experience of CMC with their patients, challenged the dominant thesis that "any communications involving the use of ICT are very prone to a certain degree of risk and threats to poor communication" (Lee et al., 2007:3). In brief, what has been systematically observed was that mediums' limited *perceived affordances*, determined the remote session's perceived levels of risk.

It is reminded Psych2's key statement that

"I could not think of even one single thing that could threat my trust-based relationship with my patients due to communicating in remote [...] Since one sees to the patient during Skype sessions, what difference would there be if they were here?" (Psych2)

Similarly, Paedia1 mentioned that

"[...] what puts me in an awkward position is the request for a therapeutic regimen when technology (ICT) cannot convey to me all necessary information." (Paedia1)

Overall, the current thesis confirms to some extent the influential yet controversial *information richness* theory (Daft and Langel, 1983), in that *affordances* influence users' medium-selection decisions. At the same time, it provides evidence that challenges the positivistic approach that *affordances* are fixed and immutable. Key statements provided by healthcare experts revealed that it is the user's potential to use the medium beyond designer's expectations and intentions, that determines the *perceived* richness or leanness of the medium. It is reminded Phys1's statement regarding the superiority of digital photos in terms of information richness compared to the one of touch as a medium for collecting haptic data.

“If it is just a skin condition, a photograph is the perfect medium [...] because I can have the photograph in front of me; I can see more details. I can enlarge it and see something that I would have missed with the naked eye.”
(Phys1)

Phys1’s statement among others’ statements, is echoing the interpretivists’ voices calling for revisiting the user-to-technologies interaction as a dynamic rather than as a static one (Majchrzak and Markus, 2012).

Moreover, the current doctoral thesis extends knowledge by unravelling and highlighting the role of *trust* as a determinant of the healthcare experts’ medium selection decision, confirming the very limited research work (Watson-Manheim and Belanger’s, 2007; Lo and Lie, 2008). Consequently, *trust* and particularly the non-expert’s *trustworthiness in terms of skills*, is added to a broad group of factors such as *affordances* (Daft and Langel, 1983), *distance*, *expediency*, *structure*, *time-factors (time-pressure)*, *accessibility of the medium* and *critical mass of users* (Trevino et al., 1987), that influence users’ medium-selection decision. It is reminded that, according to the emerging theory

the *limited perceived affordances* of the ICTs, it is possible to generate data-gaps which are expected to be “filled” in by trustworthy patients, making use of their *aptitudinal* and *communicational skills* in order to minimize or even eliminate the *communication failure* of misdiagnosis.

From a trust perspective, the emerging theory confirms Lo and Lie’s (2008) findings in that communication partners who are perceived as *non-trustworthy* in terms of *aptitudinal* and *communicational skills*, are not given access to remote modes of communication. Instead, non-trustworthy patients and carers are diverted to communication channels which are perceived to have the highest degree of information richness i.e. to the traditional clinical examination. However, the limited yet relevant research work (Lo and Lie, 2008; Watson-Manheim and Belanger’s, 2007) has not identified the special qualities that define a distant communicator as *trustworthy*. The current thesis draws experience from the patient-healthcare expert CMC and contributes to knowledge by identifying a range of skills which are necessary for minimising, not to mention totally hedging, the risks associated with CMC i.e. the *risks of understanding*, *action* and *perception* (Lee et al., 2007).

The *risk of understanding* has been identified as a one of the key risks associated with the remote nature of the CMC. Significant concerns regarding the negative effect of patients' incorrect, distorted or even false descriptions to the quality of their decisions, have been expressed by all the physicians interviewed in the current study as well as by a limited number of studies (Mort et al., 2003; Lupton, 2013). In other words, physicians expected that patients who lack the spectrum of the necessary *communicational* and *aptitudinal skills* thoroughly described in Chapter 6, it is possible to have a negative effect on their "understanding and interpretation of the information transferred". The imperative need for a *trustworthy patient*, becomes even more intense due to the lack of expertise and hence lack of *shared understanding*, on behalf of the patient. According to the physicians interviewed, the *trustworthy patient's* aptitudinal capacities to *critically think* and *learn easily*, combined with communicational capacities such as *transferring reliable subjective second-hand data with accuracy*, it is expected to minimise the *risk of shared understanding* and thus the risk of misdiagnosis.

Moreover, the current thesis challenged Lee et al.'s (2007) thesis that the *risk of understanding* has been found to be prone to technologies who can't *afford* transferring affective data (facial expressions, voice tone, voice texture, gestures etc.). However, experience drawn from the group of MHEs offered subtle indications that *being accessible* to patients via ICT, no matter their *affordances*, it is interpreted by patients as a tangible proof that they are still present to them and supportive for then even in the absence of physical proximity. Consequently, though it might be difficult for a landline to afford the warmth of a hug, it has the potential to transfer warmth through the voice tone or the words chosen for communicating empathy.

Moreover, the current thesis contributes to knowledge by providing evidence about the valuable contribution of particular *aptitudinal skills* as counterweights to the *risk of action* in the light of CMC. According to my interpretation, physicians are keen on engaging themselves in CMC sessions with patients and carers who possess basic *cognitive skills* such as *executing simple tasks* with accuracy, in order to hedge risks coming from the patients' or carers' negligence or refusal to execute the assigned tasks the proper way. For example, I would expect that patients and carers who blindly take the "right" action without a good understanding of the instruction-based message i.e. patients and carer who lack the skill of

critical-thinking, it is possible to increase what Lee et al. (2007) defined as the risk of *in-adaptive action*. In brief, physicians seem to appreciate patients and carers possessing the *aptitudinal skills* thoroughly analysed in Chapter 6 because it is expected to be able “to adapt their actions if the situation or the condition changes” (Lee et al., 2007:6).

Finally, the current thesis provides subtle indications that patients’ and informal carers’ *communicational skill* of transmitting *high-quality second-hand objective data via ICTs*, is appreciated because it has the potential to hedge the *risk of reception*. As Lee et al. (2007) highlighted, the *risks of generation* and *transmission* emerge from the user’s lack of familiarity with the ICTs used of CMC. Three physicians out of the eight interviewed, highlighted the value of communicating in remote with patients or informal carers who possess such ICT skills. It becomes easily understood that the less the patients and informal carers involved in the transmission of medical-data, the less the *generation risk*-levels and so the possibility for a *communication failure* to emerge. Overall, the current thesis contributes to knowledge from a CMC perspective in that identified a spectrum of skills that are judged as necessary for hedging risks that it is possible to lead to communication failures.

8.8 Implications for policy and practice

I hold the view that researchers in the field of social sciences produce valuable research work when they address actual issues and produce recommendations that have the potential to contribute to what societies define as quality of life. The current thesis is among the very first research works that explore the role of trust i.e. the core of the patient-healthcare expert relationship in the light of CMC via daily technologies, in a period of time when all member-countries are working towards the digital transformation of their national health systems. ICTs are expected not only to make accessible high quality healthcare services to EU citizens living in remote, but also to “enable a wider use of genomic and other information (such as molecular profiling, diagnostic imaging, environmental and lifestyle data) to help doctors and scientists better understand disease and how to better predict, prevent, diagnose and treat” (European Commission, 2018:7). The following recommendations are based on the findings emerged from the current doctoral thesis and it is anticipated to contribute in making the national health and care systems of the EU “more resilient, accessible and effective in providing quality care to European citizens” (European Commission, 2018:1).

Before moving on to the listing of recommendations, it should be made clear what constitutes a top priority for the European Commission in the health sector as well as what are challenges that should be taken into consideration. The vision of the European Commission is to make the most out of the ICTs in order to deliver to its citizens improved health services that will “increase the well-being of millions of citizens and radically change the way health and care services are delivered to patients” (European Commission, 2018:1). It is anticipated that *digitisation* can support the transition of health systems to new healthcare models centred on people’s and patients’ individual needs defined as *person-centred care*. In other words, the supply of *personalised health and care services* constitute a high priority goal for all the policy makers across the EU dealing with public health and care services. Moreover, according to the EU health policies and strategies such as the *Together for Health*, reforms and innovative initiatives are expected to make the EU health system more solid in terms of efficiency and productivity without setting at risk key priorities such as (a) social cohesion and (b) patients’ health status.

However, it should not be forgotten that the project of *digitisation* and the establishment of *personalised healthcare services*, require major financial investment at a time when national budgets are under significant financial pressure. The current financial conjuncture it is expected to be burdened from a number of adverse trends in the health sector such as the ageing population, chronic and rare diseases and a wide range of non-communicable diseases due to risk factors such as tobacco, alcohol and obesity. Furthermore, the EU health policy makers are invited to address and resolve a number of additional issues such as the unequal quality and access to healthcare services as well as a shortage of health professionals.

In response to the identified challenges, priorities and expectations, the current thesis recommends:

1. *knowing my patients* beyond their medical or biological-data profile
2. designing trust-centred policies
3. being aware of the digital-divide risk
4. making the most out of the already established IT infrastructure

8.8.1 *Knowing my patients beyond their medical or biological-data profile*

As it has been stressed within the current chapter, the establishment of *personalised healthcare services*, constitutes one of the top-tier goals for the EU health policy makers. *Patient-centred* services are built upon the principle that the more health or biological data I have for the patient, the more effective therapies can be delivered and thus the more efficient cost-management can be achieved. I would express the concern that any effort to design and deliver such an ambitious type of tailor-made health service, requires from healthcare experts to be aware of their patients beyond their medical or genomic profile. The findings emerged both from the current thesis as well as from a limited yet rising number of papers, indicated that it is of critical importance for healthcare experts providing implementing medical actions in remote, to *know* their patients' in terms of personality, attitudes, behavioural patterns, risk profile as well as in terms of skills. The perceived risk of missed-under-or-misdiagnosis as a consequence of the constraints imposed to human sense due to the remote mode of communication, urges the need for the healthcare experts to be aware of their patients' skills. A limited number of research work has demonstrated that medical data themselves can't guarantee an accurate medical decision (Mort *et al.*, 2003; Mort and Smith, 2009; Lupton, 2013).

Consequently, I would recommend to health policy makers to avoid approaching patients solely as a cluster of medical data that it is possible to access in remote. I would consider that suggestion as a valuable one especially for cases where patients are actively involved in the management of their own disease and thus, they are expected to perform a number of tasks far from healthcare experts' supervision. I hold the view that the sensors of smart, wearable and affordable -in terms of money- mobile devices it is technically possible to replace doctor's hand as a mean for collecting medical-data. Nevertheless, it should not be that not all patients are equally capable of managing risky situations or making the best possible decisions in the light of an emergency. To sum up, I would encourage health policy makers to reconsider the option of *personal doctor* i.e. the healthcare professional who will be in charge of taking care and monitoring an assigned portfolio of cases-patients. I would expect that such a model could help towards the faster implementation of a tailor-made health service since it would help healthcare experts in charge to have a broader knowledge of their patients both in technical terms but also in terms of skills and capabilities.

8.8.2 Designing trust-oriented systems and policies

As it has been stressed, the expensive project of digital transformation in the EU is taking place at a period of time when public spending on healthcare follows an upwards trend and is expected to do so. So, it becomes understood that the limited funds available for the digitisation project leaves no room for a non-sustainable model with limited life expectancy. At the same time, there are voices such as the ones of Larson et al. (2016) echoing Giddens' (1990) and Popper's (1962) thesis *that trust in professionals and expert systems* should not be taken for granted. Moreover, a recent study of the European Commission (2018) underlined that citizens' trust in contemporary technologies should not be taken for granted too. In particular, the study "identified concerns specific to the electronic sharing of data, namely the risk of privacy breaches, cybersecurity risks and the quality and reliability of data" (European Commission, 2018:4). Overall, the socioeconomic environment within which the project of digital transformation takes place is not ideal. Given the current circumstances, I hold the view that in our *risk society* where new risky technologies are designed to hedge the risks depicted from the existing ones, it is vital to design trust-centred e-health systems and policies. Investing enormous amounts of money in the digitisation of the EU health system without having assessed or even estimated its effect in terms of trust in professionals or systems, would put at risk its returns in terms of sustainability and money.

According to the emerging theory of the current thesis, the risk of misdiagnosis, as a product of the limited information richness capacity of the medium employed for CMC, urges the need for a *trustworthy patient* in terms of skills. In other words, the emerging gap in terms of medical-data it is expected by the physicians to be fulfilled by the communicational, aptitudinal as well as managerial capacity of the patient or carer in charge. Respectively, the limited presence or even total absence of medical data-gap reported by the MHEs due to the adequate performance of the commercial videoconference applications and telephone devices in terms of affordances, urged no need for a skilful patient. At first glance it seems that the smaller the identified gap of medical-data, the smaller the need for a skilful patient. Consequently, accepting that "the active cooperation between care professionals and patients" is one of the basic ingredients for the successful implementation of the digital transformation, it becomes understood that telemedicine applications, platforms and systems, should not shake trust issues up. Shaking trust issues up could set at risk the core of the patient-healthcare expert

relationship and thus the sustainability of any initiative to make the most out of the latest ICTs for the best of the EU citizens health and well-being. Consequently, it might be useful for health policy makers to be aware that any telemedicine application or system should be designed based on the informational needs of each medical specialty. I would expect that the minimisation of the medical-data gap, combined with awareness on behalf of the healthcare expert about “who is my patient”, would make patient’s contribution in terms of skills less necessary. That would contribute to making *over-the-counter telemedicine services*, accessible even to patients who lack the necessary communicational, aptitudinal and managerial skills, minimising the risk of an emerging *digital divide* due to a gap in skills possession.

8.8.3 Being aware of the digital divide risk

According to the OECD (2018), digital divide refers to “different levels of access and use of information and communication technologies (ICTs) and, more specifically, to the gaps in access and use of Internet-based digital services” (p. 11). It is common knowledge that digital divide, PC penetration and internet access tend to be lower for elder people due to skills possession. I personally hold the view that the exclusion of the elder citizens from a number of revolutionary e-health services, especially in the EU territory where the challenge of ageing dominates, it would signal the short-term life expectancy of the system. Any e-health policy or platform that will fail to take into account the special needs and characteristics of the elder ones (limited ICT literacy or digital health literacy etc.) it is also far from the vision of equally delivering personalised medicine services to all the citizens of the EU.

Furthermore, the EU health policy makers expect that e-health it is possible to “facilitate socioeconomic inclusion and equality, quality of life and patient empowerment through greater transparency, access to services and information and the use of social media for health” (European Commission, 2012:4-5). Consequently, if patients’ empowerment goes through accessible e-health services, then policy makers should pay attention to any possible cause that could potentially exclude any group of the EU population and especially the one of elder ones. As the current thesis demonstrates, the lack of skills could be one possible cause. It is common sense that if the sustainability of the emerging e-health services demands skilful patients, health policy makers should work proactively by equipping EU citizens with the necessary skills via a variety of channels. It has been since 2013 with the Competitiveness and

Innovation Programme and continuing under Horizon 2020, when the European Commission supports activities aiming at increasing citizens' digital health literacy.

8.8.4 Reusing existing ICT infrastructure: the *over-the-counter telemedicine* solution

The European Commission (2018) suggests that innovation in terms of new technologies, products and organisational changes, is the path leading to health promotion, disease prevention and delivery of person-centred integrated health services. Although I share EU health policy makers' view, I would add that at a time when health and social care systems are found to be under financial pressure, it should worth assess what could be achieved with the existing ICT infrastructure instead of investing or relying solely on new technologies.

In particular I would encourage the funding of research regarding how asynchronous and synchronous ICTs that constitute part of our daily routine (regular phone-calls, e-mail and texting services, applications supporting data exchange such as videos and photos etc.) could contribute to the implementation of the set targets. I would urge policy makers not to ignore mobile phones' potential to capture and transmit medical data of high-definition either in a video or a photo format. It should not be forgotten that the transmission of rich medical data are less susceptible to misinterpretation compared to verbal data which are highly susceptible to distortion due to the limited communicational or speaking skills of the patient or carer in charge. Paedia1 stressed the potential of daily technologies such as mobile phones' embodied cameras to capture data that would be difficult to describe or capture in a paediatrician's office.

“video is a good tool. It has been necessary to document a child needs to have its adenoids excised; it has led me to examine the child and refer her/ him to a neurologist [...] I see the child (in the video) do a weird movement or s/he makes a strange noise or has a strange cough while sleeping” (Paedia1)

Nevertheless, even lean mediums in terms of information richness capacity such regular phone or mobile phone devices, have the potential to have a positive impact on the trust-sensitive patient-healthcare expert relationship. It is reminded that all MHEs unanimously supported that *being accessible* to their patients via ICT is an alternative way of *being there* for them. However, it was Psych1 who clearly set the perceived affordances parameter by supporting

that being accessible to her patients via ICT, no matter what's their affordances, it is interpreted by patients as a tangible proof that their MHEs in charge are still present and supportive even in the absence of physical proximity.

“If the other person feels that you are available in any way, be it Facebook, ‘pigeon mail’ or anything else, then they feel comfortable. They feel secure, they feel that much better.” (Psych1)

For example, I would consider the delivery of mental-health and well-being services i.e. talk-therapy sessions to citizens across the EU territory via built-in videoconference technologies or even regular landlines, as a cheap and a well-promising project. That might be a first step towards the establishment of a low-budget tele-mental-health service in a region i.e. the EU, where mental disorders affect more than a third of the population while there is still much to be done for preventing the influx of new cases of depression (Cuijpers et al., 2016).

To sum up, the digital transformation in the public health sector takes place at a time when the EU presses down for cost-cutting actions in the health and long-term care domain while at the same time trust in experts and systems is challenges. The abovementioned socioeconomic landscape urges for digital solutions that have been “designed purposefully and implemented in a cost-effective way” (European Commission, 2018:1). The emerging theory demonstrated within the framework of the current thesis as well as the secondary findings, indicate that any attempt for digitising public health systems across the EU, should be trust-sensitive promoting mutual trust between healthcare experts and laypersons. There are plausible indications that the digitalisation of health services is difficult to be functional in the absence of a skilful patient. Consequently, measures should be taken for equipping citizens, patients and informal carers with the skills required for making a digitalised health system operational. However, measures should be also taken in order to avoid the exclusion of the elder ones from accessing the emerging healthcare model due to lacking the necessary skills. Finally, it is suggested that extended research should be done over what it has been defined as over-the-counter telemedicine and its possible contribution to the achievement of the desirable outcomes.

8.9 Research gaps and contribution to knowledge

Exploring the role of trust in the light of the patient-to-healthcare expert remote communication has been a challenging task due to the limited prior research in this field.

Thorough search engine research for scholars led me to the conclusion that there has been marginal research about the patient-healthcare expert CMC. That limited number of papers found came from the wider field of telemedicine and telecare (Andreassen *et al.*, 2006; Nilsson *et al.*, 2010; Shea and Effken, 2008; Delbanco *et al.*, 2004; Yager, 2001; Bjerke *et al.*, 2008; Bültzingslöwen *et al.*, 2005), and this has been thoroughly discussed and analysed in Chapter 3. Although I used to worry, especially at the beginning of my PhD project, about whether or not I had identified an actual research gap, it was Lee and Zuercher (2017), who published six years later, came to verify my initial estimation that too little is actually known about the patient-physician remote communication. It is worth underlining that we knew even less about the role, value and function of trust - as a primary matter of this relationship - in the light of the patient-healthcare expert remote communication (Andreassen *et al.*, 2006; Nilsson *et al.*, 2010; Shea and Effken). Although there is rich literature reviewing trust in the patient-healthcare relationship, marginal knowledge has been available about its role and, therefore, its value in the setting of CMC. The under-researched element of trust in the light of the patient-physician remote communication has been verified by Lee and Zuercher (2017), too. Additionally, what made my PhD project even more challenging was the limited knowledge we had on the trust-based relationship from the healthcare expert's perspective (Calnan and Rowe, 2006).

Lastly, although there have been a number of CMC theories attempting to capture the effect of remote communication via ICT in the communication partners' relationship, these have offered ideas that are both controversial and conflicting about the effect of CMC on social and interpersonal interaction. Moreover, all these CMC theories have failed, in a way, to capture the role of trust in the setting of remote communication. Indeed, there is ample literature exploring the element, value and role of trust in the setting of virtual or remote work (Bos *et al.*, 2002; Zheng *et al.*, 2002; Wilson *et al.*, 2005; Riegelsberger *et al.*, 2003; Lo and Lie, 2008). However, this group of papers, which has been thoroughly analysed and discussed in 3.2.1, was used to study the element of trust among team-members without power asymmetries between them. What makes the study of the patient-healthcare professional remote communication different from the literature mentioned above is the significant power asymmetries that exist between these two parties.

Overall, the limited number of relevant research papers not only rendered the PhD thesis challenging, but also opened an opportunity for actual contribution to knowledge, especially in the field of the patient-healthcare expert remote communication.

In terms of contribution to knowledge, the current PhD thesis provides, for the first time, advanced knowledge that is not about the patient-healthcare expert CMC, in general, but specifically about the role of trust in the remote communication setting in response to the call for research addressed by Andreassen *et al.* (2006), Santana *et al.* (2010), as well as Lee and Zuercher (2017). In the light of a gap identified in medical data, *patients' trustworthiness* in terms of *communicational*, *aptitudinal*, *managerial* and, finally, *social skills*, has been found to play a key-role in physicians' decisions as to whether or not to respond to patients' requests for implementing any medical act, such as guidance regarding medication or, even, diagnosis. Although MHEs did not seem to share physicians' stance and experiences, it was the former who emphatically supported that the accessibility offered by ICT has the potential to nurture, maintain and, ultimately, build trust, given the MHE's availability, as an important variable.

At this point, it should be highlighted that this is also the first time that light has been shed on what I define as *over-the-counter telemedicine*, i.e., the patient-healthcare expert remote communication strictly for medical purposes via ICT, designed for private use and commercial purposes rather than for medical ones. After thorough literature review research, both at earlier, as well as later stages of my PhD project, I concluded that there was a dearth of studies concerning everyday technologies and health. One possible explanation for this research gap could be the limited interest that the research community has shown in the way healthcare professionals experience trust-based relationship with their patients (Calnan and Rowe, 2006). However, off the record discussions with healthcare professionals and researchers revealed the narrowly clinical focus of the telemedicine domain as a second possible explanation. Most research report findings from pilot telemedicine platforms seem to ignore developments in everyday technologies pervading healthcare, as well as other aspects of our social activities. Andreassen and Skrøvseth (2016) urge researchers to study "how to use the technology to achieve the best benefit for the patients" (page not available) rather than 'how to disseminate telemedicine and e-health technologies in the healthcare sector' (page not available). My research work on how to utilize every day technologies in the daily patient-healthcare expert

remote communication without jeopardizing trust is a tangible response to Andreassen's and Skrøvseth's (2016) call for research.

Another 'first' should also be underlined here, i.e., that most patient-doctor literature approaches to date highlight a trust-based relationship as if only the patient's trust matters (patient's trust). Another noteworthy point is that what we have had so far, have been only subtle, yet limited, indications that the patient-doctor relationship is one based on *mutual* trust (Cook *et al.* 2004; Thorne and Robinson, 1988; Irwin *et al.*, 1989; Roter and Hall, 1992; Miller, 2007; Merrill *et al.*, 2002; Bültzingslöwen *et al.*, 2006; Jain *et al.*, 2006; Thom *et al.*, 2011). My research, similarly to that by Thom *et al.* (2011) is among the first to provide a detailed map of the trustworthy patient/carers profile, thus indicating that the patient-doctor relationship is one based on mutual trust, especially in the light of remote communication.

Finally, though this is not the first time that a positive association between the elements of *trust* and *accessibility* provided by ICT has been reported (Shea and Effken, 2008; Nilsson *et al.*, 2010; Simpson, 2009; Delbanco *et al.*, 2004; Yager, 2001, Bültzingslöwen *et al.*, 2005; Bjerke *et al.*, 2008), my study is one of the first to report that accessibility provided by ICTs should be approached as an opportunity for maintaining or empowering trust in the patient-healthcare expert relationship (Bjerke *et al.*, 2005).

8.10 Limitations

I would consider as a limitation physicians' limited availability in terms of time as opposed to that of MHEs. As already stressed in the methodology chapter, physicians often had a very limited amount of time for interviews, which, sometimes, did not exceed forty-five minutes. Follow-up interviews became a challenge, too. Based on my initial estimations, I should have easily accomplished 15 interviews with physicians rather than eight. Cancellations were frequent, while often, during our interviews, their mobile phones would ring, interrupting the flow of our interview.

At this point it is of critical importance to underline that it was not my initial intention to approach physicians as a different group from mental-health experts. As I have stressed in the methodology chapter, I recruited physicians and mental health experts based on the reasonable assumption that what they all have in common is that they all gain their patients'

trust because of their healing expertise. However, during the data-collection stage, I found that physicians experience remote communication with their patients in a very different way from that of MHEs'. Bearing in mind that physicians demonstrated limited availability even from the earliest stages of my research, when I undertook a small number of brief pilot interviews, I made my decision to interview physicians before MHEs.

Nevertheless, interviewing MHEs would not be a problem, since most of them were recruited through personal networks, and so the risk of cancellation was minimal. Once I finished the data-collection and the analysis stages (coding) with physicians, I 're-visited' the rest of my interviewees, i.e. MHEs, with the codes and themes that had been developed up to that point with physicians. Surprisingly, every single interview with MHEs was a *negative case*. In other words, MHEs challenged the existence of the *trustworthy patient* and, therefore, the validity of my emerging theory, according to which only *trustworthy patients* should be given access to remote communication by their physicians. Although the first *negative cases* caused me feelings of doubt, it then became even clearer that MHEs experienced remote communication in a very different manner from that of doctors, for the reasons analysed in chapter 7. So, I finally found myself with two different groups of interviewees comprising eight persons each, instead of one group of sixteen.

I do not ignore that the difficulty in recruiting an extra number of physicians in order to 'delineate and develop' (Charmaz, 2014:199) the attributes of the *trustworthy patient* or *know my patient* themes probably deprives my PhD thesis from achieving the *theoretical saturation* state, i.e., "the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory" (Charmaz, 2014:345). Instead of pretending that "no new concepts emerged from the data" (Urquhart, 2013:9) so that *theoretical adequacy* (Charmaz, 2014:90) may be achieved, I recognise the small number of interviewees per group and the limited availability of doctors in terms of time as a limitation. Although I recognise that it would be a fallacy to proclaim *theoretical adequacy* in the absence of *theoretical saturation*, I hold the view that it is yet possible for new knowledge to emerge, contributing to the advancement of understanding under-explored areas of our social lives, such as that of the patient-healthcare expert remote communication.

8.11 Suggestions for future research

To my knowledge, the current thesis research is the first one that has attempted to explore the role and, therefore, the value of trust in the light of the patient-healthcare expert remote communication responding to the call by Andreassen *et al.* (2006), Santana *et al.* (2010), as well as Lee and Zuercher (2017) for further research. It becomes obvious that the field of patient-healthcare professional remote communication, especially through commercial devices designed for private rather than medical content communication, is not a mature research field in terms of research activity. Instead, I would consider it an emerging research field, especially due to rapid developments in the ICT field.

Firstly, I would urge researchers to explore the role of trust per medium (i.e., texting services, videoconference applications, communication via social networking platforms), as well as per specialisation. I would consider that suggestion for future research as of critical importance because, as it has already been demonstrated, *affordances* vary depending on the user (*perceived affordances*), as well as on the specialisation. Consequently, I would invite researchers from the dynamic field of sociology of e-health and telemedicine to become more aware of the relevant CMC literature. What should be kept in mind is that “information” itself is the primal matter of our *post-modern* aka *digital societies*. The discipline of CMC has a long-term tradition in studying human-to-human computer-mediated interactions from an information (data) perspective. Therefore, it has the potential to enrich the theoretical and methodological toolkit of social scientists who study the impact of digital health transformation in trust, power and risk terms.

Moreover, it would be of significant research interest to study the aspect of a *physician's clinical experience (in terms of years)* as an independent factor that may affect their attitude towards any remote mode of communication with their patients. As Phys1 stressed:

“There are many times when some of my colleagues refuse to offer medical advice over the phone. I do not do it. I do not mean that, ‘I am the only one who is right’. The truth is that most times I give medical advice over the phone - **because I have extensive clinical experience** - when I see that I trust the patient [...].” (Phys1)

Phys1 attributed her stance over remote communication by phone to her extensive *clinical experience*. Similar, yet subtler statements, were made by Diab1 who mentioned that:

“It is a question of **experience**... I took different actions 20 years ago, when I was starting off in my profession, and I take different actions now. I was rasher, more... enthusiastic, right? Now I know that there are also those unusual, rare, strange symptoms [...] but in the past, I was also more aggressive; I am no longer like that.” (Diab1)

Light should also be shed on physicians’ *computer* and *ICT skills*. Paedia2 and Phys1 made two contrasting statements. In particular Phys1 mentioned that:

“If it is just a skin condition, a photograph is the perfect medium [...] because I can have the photograph in front of me, I can see more details. I can enlarge it, see something that I would have missed with the naked eye” (Phys1),

in sharp contrast to Paedia2 who mentioned that:

“I usually don’t like to diagnose based on a photograph (over the phone), because, you know, that is very dangerous [...] I tell them I get a different image in person than I do from a photo; it is a completely different picture” (Paedia2).

It seems that *computer skills* affect the way physicians experience remote communication and finally make their medium-selection decision. The question emerging at this point is: “*How would Paedia2 experience remote communication through save-and-forward applications, if she had the training to edit photos received by patients?*”. I would consider physicians’ *computer skills* as an extra factor that should be studied as part of their remote communication experience.

Moreover, the mental-health experts’ experiences, i.e., that the *accessibility* offered by ICT has the potential of nurturing, building, and maintaining the bond of trust with their patients also raises a concern. As repeatedly mentioned, patients whom physicians consider inappropriate for remote communication are the ones who lack trustworthiness in terms of skills. Consequently, if physicians hesitate or - even worse - avoid being accessible from a distance to individuals who lack skills, such as managing ‘easy tasks’ on their own (aptitudinal skills) or

effectively responding to a perceived critical event (managerial skills) or, even, accurately transferring necessary data (communicational skills), this means that we are probably facing an inequality issue, i.e. that lack of accessibility may well be interpreted by patients as a form of exclusion with unpredictable consequences in terms of trust. In a follow-up interview, Pedia1 mentioned a case in which the patients let her know that though they continued to trust her, they had made the decision not to visit her anymore because she was not as accessible as they would like her to be.

“There was a couple whose child I used to look after and who called just to thank me for my services, letting me know, at the same time, that they would like to work with a new paediatrician because - according to them- I was not accessible enough.” (Pedia1)

Four out of the eight physicians interviewed highly linked patients’/carers’ ability to identify and accurately and reliably transfer critical data with their educational level. As ObGyn1 stressed:

“They (patients of a low educational level) make my life difficult as I have to explain everything in really simple terms so they can get it” (ObGyn1)

Like ObGyn1, Phys1 and Pedia3 reported that educational levels are associated with patients’ aptitudinal skills, i.e., the patients’ ability to identify emerging risks and respond appropriately. It should be kept in mind that a patient’s aptitudinal skills are an inherent trait of the trustworthy patients’ makeup, and enables them to gain or lose remote access to their physician.

“They cannot assess the severity of a condition because of their low educational level, living conditions and low socio-economic level.” (Pedia3)

This quote raises a number of questions and concerns, such as how patients/carers could possibly experience such lack of access.

As already mentioned, MHEs unanimously supported that *being accessible to their patients* via ICT is an alternative way of “*being there*” for them, which is perceived as a tangible form of care. Consequently, it could reasonably be assumed that physicians’ hesitation or refusal to be

accessible from a distance could possibly be interpreted by the patient as reluctance or, even, refusal on the part of the physician to stand by the patient, putting trust in professionals at risk.

Similar concerns with regard to inequality issues, in light of the patient-physician remote communication, have also been reported by Lee and Zuercher (2017), who, in their research, mentioned a limited number of papers according to which “younger, male, more educated and more urban patients were more likely to appreciate and have a positive attitude toward CMC discourse in this relationship” (p. 6). Rosen and Kwoh (2007) also reported that fewer than 50% of the families enrolled in a public health insurance plan contacted their general practitioner via email. Similar to Rosen and Kwoh’s (2007) socioeconomic perspective, ObGyn1 and Pedia3 reported that patients and carers, whom they consider non-trustworthy and, therefore, inappropriate for remote communication, are found to belong to lower socioeconomic strata.

I share the view of Andreassen and Skrøvseth (2016) that researching *how* the adoption of ICT by the healthcare system changes the delivery of care should be of high priority. However, I also hold the view that the role of *trust* should be a priority for researchers, too, if we want telemedicine strategies and programmes designed to be sustainable. It should not be forgotten that trust lies not only at the core of the patient-healthcare professional relationship, but also at the core of our society, bringing cohesion to social life, while reducing complexity in the postmodern environment of chance and risk (Luhmann, 2000).

8.12 Concluding remarks

The research aim of the current PhD thesis was to provide advanced understanding of how healthcare professionals experience remote communication with their patients, placing special interest on the element of trust and making use of original qualitative evidence. According to my research output, trust matters for physicians yet not for mental health experts. A *patient’s trustworthiness* in terms of communication, aptitude, management, as well as social skills, influences a physician’s decision whether to respond to a patient’s or informal carer’s request for computer-mediated communication. In sharp contrast to physicians, mental-health experts did not recognise the construction of the *trustworthy patient*, though they recognise that the patient-MHE relationship does, indeed, take two. Nevertheless, it was the MHEs who

underlined that being accessible to their patients by any means is interpreted as a form of *'being there, being present'* for them and *'being supportive'*. That form of presence has the potential to nurture, build or even empower trust, i.e., the cornerstone of the patient-healthcare expert relationship. Trust research in the field of the patient-doctor remote communication should be of an ongoing nature, given that ICT grows and advances on a daily basis. Finally, I would invite researchers from the dynamic field of sociology of e-health and telemedicine to become more aware of the relevant CMC literature and its theoretical properties.

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Appendices

Consent Form

Title of PhD Project: Re-examining patient-doctor trust relationship in the digital era.

Please tick box if your answer is "Yes"

1. I confirm that I have read and understand the information sheet overleaf. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I agree to participate in Vasileios Kalyvis PhD project regarding trust issues between the doctor/therapist and the patient in the digital era. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
4. I understand that interviews and any material produced will be used for research purposes and extracts will be anonymised before inclusion in any research reports, conference presentations or academic publications. ☐
5. I agree to the interview being audio recorded and my name and all personal identifiers to be anonymised. ☐

Name of participant	Date	Signature

Name of person taking consent	Date	Signature

When completed, 1 for participant; 1 for researcher site file

Information for participants

Dear Sir or Madam,

My name is Vasileios Kalyvis and I am a PhD student at the Business School of Manchester Metropolitan University (UK). My PhD thesis aims to study the MHE/patient-to-doctor relationship when the two parties do not communicate face-to-face during their therapeutic sessions but via classical or contemporary information and communication technologies (ICT) such as landlines, mobile phones, SMS services, e-mail services, videoconference applications or others. Trust is the element of the patient-to-doctor relationship that I am intended to explore in depth. Semi-structured interviews will be employed for gathering data either through face-to-face interviews or via Skype or phone. There is not offered any remuneration for research participants for their contribution to my research project however you can have access to results and findings upon request after the successful completion of that PhD thesis.

Vasileios Kalyvis

(BSc, MSc, PhD Cand.)

Contact details

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Nickname	CV Details			ICT utilised for remote communication with patients						Interviews conducted via:	Interviews duration	
	Expertise	Academic Qualifications	Professional Experience (in years)	Phone Calls (Mobile)	Texting services	Email	Video-conference	Data exchanging			1st Interview	Follow-up
								Photos	Videos			
Pedia1	Paediatrician	MD, PhD candidate	>5 years	*	*	*		*	*	Skype	01:17:25	38:27:00
Pedia2	Paediatrician	MD, PhD	>5 years	*	*	*		*	*	Skype	0:53:00	00:17:20
Ophthalm1	Ophthalmologist	MD	>3 years	*		*	*	*		Skype	01:10:00	00:17:00
DramaTh1	Psychiatrist oriented in Dramatherapist	MD, BADTh	>25 years	*	*		*			Face-to-face interviews	00:59:00	<i>focused questions sent by email</i>
MHE1	Psychotherapist (Psychoanalyst)	BSc, MSc in psychoanalysis	>10 years	*	*	*	*			Face-to-face interviews	00:45:00	<i>focused questions sent by email</i>
MHE2	Psychotherapist (Clinical Psychologist and Trainee in Dramatherapy)	BSc, MSc	>10 years	*	*		*			Skype	00:45:00	00:44:00
MHE3	Psychotherapist	Qualified dramatherapist	>10 years	*	*		*			Skype	00:36:00	00:30:00
Psych1	Psychiatrist specialised in psychotherapy	MD	>5 years	*			*			Skype	01:07:00	00:16:33
DramaTh2	Dramatherapist	BADTh	>5 years	*	*		*			Skype	00:50:00	<i>n/a</i>
MHE6	Psychotherapist specialised in patients suffering from alcohol addictions	BSc	>10 years	*	*		*			Skype	00:43:00	<i>focused questions sent by email</i>
ObGyn1	Obstetrician-Gynecologist	MD	>10 years	*	*			*		Skype	00:51:50	00:14:30
Diab1	Physician specialised in diabetes	MD, PhD	>20 years	*	*			*		Face-to-face interviews	00:45:00	00:17:00
Phys1	Physician/ Infectious Diseases Expert	MD	>5 years	*	*			*	*	Mobile phone call	00:43:00	<i>n/a</i>
Dent1	Dentist	MD	>10 years	*	*			*		Face-to-face interviews	00:26:00	<i>n/a</i>
Psych2	Phychiatrist oriented in psychotherapy	MD	>20 years	*		*	*			Skype	00:35:00	<i>focused questions sent by email</i>
Pedia3	Pediatrician	MD, MSc in Hospital management	>5 years	*	*			*		Skype	00:46:00	<i>focused questions sent by email</i>

Healthcare experts' Matrix

The *perceived affordances* analysis table

Interviewee	Incidence No.	Abstract	Medium	Perceived affordances of the medium (in terms of data)	(Medical) Data transferred to the doctor	Data taxonomy	Accessible data by the doctor in remote [?]	Data Gap identified [?]	Should additional data be collected [?]	Perceived risk
Paedia1	1	Therefore, 'his/her tummy hurts' may be a tonsillitis or it may be that 'I am angry you stroked my brother and not me', or it might well be appendicitis.	phone-call	verbal+sound	verbal	2nd-hand subjective	N	Y	Y	misdiagnosis
	2	...here I have the picture of a lovely young lad, who, as you see, has red cheeks and a small eczema, so I take photos of lesions - mainly skin lesions - which people often ask about and one can, most times, recognize what they are	photo	visual	photo	2nd-hand objective	Y	N	N	regular
	3	What does raise an issue is when I receive something that shows a piece of skin and they ask me what it is. They drop this before you demanding an immediate diagnosis, which may or may not be clear cut.	photo	visual	photo	2nd-hand objective	Y	Y	Y	misdiagnosis
	4	...quite often I am told 'I opened the mouth and saw some white things down the throat'	phone-call	verbal+sound	verbal	2nd-hand subjective	N	Y	Y	misdiagnosis
	5	"I see the child do a weird movement" or "s/he makes a strange noise or has a strange cough, while sleeping"	phone-call	verbal+sound	verbal	2nd-hand subjective		Y	Y	misdiagnosis

6	So, video is a very good tool. It has been necessary to document that a child needs to have its adenoids excised; it has led me to examine the child and refer her/him to a neurologist.	video	visual+kinetics +sound	visual+kinetics	2nd-hand objective	Y	N	N	regular
7	I receive telephone calls from parents of children who with respiratory problems and may have dyspnoea/shortness of breath at night. At such moments you have to tell them how much cortisone should be taken, in essence and, if this does not help, the next step in a short while will be to go to the nearest emergency department.	phone-call	verbal+sound	verbal	2nd-hand subjective	N	N	N	misdiagnosis
8	...the *****watch will not really help much [...] with asthmatic children, because its sensors measure and record oxygen saturation.	wearable device	physical-data	physical data	on-line	Y	N	N	regular

Interviewee	Incidence No.	Abstract	Medium	Perceived affordances of the medium (in terms of data)	(Medical) Data transferred to the doctor	Data taxonomy	Accessible data by the doctor in remote [?]	Data Gap identified [?]	Should additional data be collected [?]	Perceived risk
Diab1	9	a colleague whose son was a diabetic, could monitor at any given moment the son's blood sugar levels, although he was in New York and his son was playing football in San Francisco; [...] this doctor had a sense of security.	wearable device	physical-data	physical data	on-line	Y	N	N	regular

Interviewee	Incidence No.	Abstract	Medium	Perceived affordances of the medium (in terms of data)	(Medical) Data transferred to the doctor	Data taxonomy	Accessible data by the doctor in remote [?]	Data Gap identified [?]	Should additional data be collected [?]	Perceived risk
Paedia2	10	I may be that someone has sent a photo; of course, I usually don't want to make a diagnosis over the phone, based on the snapshot, because it is well known this is taking a big risk; they tell you I sent you a photo of a rash; I tell them that what I can perceive when I have the patient before me and what can be seen in a photo are two totally different things.	photo	visual	visual	2nd-hand objective	Y	Y	visual+haptic	misdiagnosis
	11	There was a child with a cough and breathing difficulty; obviously the mother did not want to bother me [...] and the symptoms she was describing in the text message convinced me that it was not something that could be ignored (to be continued below) ignored <i>(to be continued below)</i>	SMS	written	written	2nd-hand subjective	N	Y	Y	misdiagnosis
	12	I called her, although she had messaged me, and asked her "What is going on?"	Verbal		verbal	2nd-hand subjective		minimised	visual+sound	misdiagnosis
	13	I remember a phone call I had received concerning a rash. I could not make head or tail of what I was told. I said I cannot do anything if I don't see the child. Of course, there was a problem with the way s/he used words. [...] When it comes to rashes, I cannot tell, if I don't see the child.	phone-call	verbal+sound	verbal	2nd-hand subjective	N	Y	Y: visual+haptic	misdiagnosis

14	In general, rashes are difficult to deal with and draw a conclusion over the phone. It happens - I cannot receive reliable information, so I have to say I must see the child.	phone-call		verbal	2nd-hand subjective	N	Y	visual	misdiagnosis
15	If a parent sends me a video of a 3-month old baby coughing and asks me for a diagnosis, I'll tell them "The video is of no help to me; I want to see the child." In a clinical examination one sees more things than what comes up on a video. There are indirect signs of a disease and direct ones you have to see when you examine the child.	video	visual+kinetics +sound	visual+kinetics+ sound	2nd-hand objective	Y	Y	Y	misdiagnosis

Interviewee	Incidence No.	Abstract	Medium	Perceived affordances of the medium (in terms of data)	(Medical) Data transferred to the doctor	Data taxonomy	Accessible data by the doctor in remote [?]	Data Gap identified [?]	Should additional data be collected [?]	Perceived risk
13	16	It did happen that I received a phone call from a mum, who told me that the child had small spots that were not puffy, did not have a pimple, are not red; they are kind of green, and so on. Whatever the description, of the actual spots, I am not God; I have to see them!	phone-call	verbal	verbal	2nd-hand subjective	N	Y	Y: visual+haptic	misdiagnosis
	17	When, for example, it is not a nappy rash, then, I can tell from the e-mail message or a photo - the same goes for an insect bite.	photo	visual	visual	2nd-hand objective		N	visual	regular
	18	I can't tell scarlet fever from a photo.	photo	visual	visual	2nd-hand objective	Y	Y	Y: visual+haptic	misdiagnosis
	19	A recent example of a mother whose child "I have raised", sent me a photo of a skin symptom. I phoned her and told her: "Vicky, I don't like what I see. I want to take a close look at the child!" [...] In other words, the photo on its own tells me nothing and it is not reliable.	photo	visual	visual	2nd-hand objective	Y	Y	Y: visual+other	misdiagnosis

Paedi:	20	Beyond the photo, when a child has spots, one has to examine the throat/tonsils, for example, to check if it might be a coxsackievirus case, which is quite common.	photo	visual	visual	2nd-hand objective		Y	visual+other	misdiagnosis
	21	When they call me, most mothers tell me 'there is a spot on the hand and the leg, as if it has been bitten' and I say "Only the hand and the leg?" and she says "Yes, only in the palm." So I go, "Oh, I think something else is going on. Why not bring the child over to me?" Finally, it was a case of viral infection [...] the mother had not seen the rest that were at other sites, which I did notice during the examination.	phone-call	verbal	verbal	2nd-hand subjective	N	Y	visual+physical	misdiagnosis
	22	However, when it is something really simple, for example, nappy rash or a atypical/localised dermatitis - something not threatening for the child - I'll tell them "Use a hydrating cream" for the atypical dermatitis, "use some cream or ointment, or St. John's wart oil on the nappy rash and see how it goes and we can talk again in 1-2 days."	photo	visual	visual	2nd-hand objective	Y	N	N	regular

Interviewee	Abstract	Medium	Perceived affordances of the medium (in terms of data)	(Medical) Data transferred to the doctor	Data taxonomy	Accessible data by the doctor in remote [?]	Data Gap identified [?]	Should additional data be collected [?]	Perceived risk
Ophthalm1	23 Once a friend called me from a remote place and said to me 'My eye hurts'. Now she may be describing what she is feeling wrongly. Or she may be using the wrong words for what she sees in her eye (<i>to be continued in the cell below</i>)	phone-call	verbal+sound	verbal	2nd-hand subjective	N	Y	Y: visual	misdiagnosis
	24 I told her to send me 3-4 good photographs in natural light. It was a sty. (<i>to be continued in the cell below</i>)	photo		visual	2nd-hand objective	Y	Y	Y: verbal	misdiagnosis
	25 But we talked after I had received the photos. She told me her problem and what she felt and I asked her. 'Is it better or worse? How long has it been bothering you? How much of a bother is it? What do you feel?	phone-call		verbal	2nd-hand subjective		N		misdiagnosis
	26 If you give me a photograph of a fundus, I will tell you it is a giant cell arteriitis. I'll tell you it is an obstructed artery.	photo (produced by medical equipment)	visual	visual	third-party	Y	N	N	regular
	27 Integrated teleophthalmology system: Low Cost Remote Controlled Slit Lamp in Order to Provide Teleophthalmology Opinion Services to Rural Areas and Islands. That system is regarded as a self-funded invention by the interviewee that has been tested and applied in a major state Ophthalmology Clinic in Athens.	mobile phone camera	visual+kinetics+sound	visual+kinetics	first-hand data	Y	N	N	regular

Interviewee	Incidence No.	Abstract	Medium	Perceived affordances of the medium (in terms of data)	(Medical) Data transferred to the doctor	Data taxonomy	Accessible data by the doctor in remote [?]	Data Gap identified [?]	Should additional data be collected [?]	Perceived risk
ObGyn1	28	Text messages concern complaints such as, small pains, vaginal discharge [...] to tell you the truth, I would be very cautious in answering to a text message. (to be continued in the cell below)	SMS	written	written	2nd-hand subjective	N	Y	Y: verbal	misdiagnosis
	29	I would definitely prefer to talk on the phone and then, if I realised that the problem was not serious, in other words, if my diagnosis would not be of any serious impact, I would offer a diagnosis [...] I would prefer an SMS from a patient whom I know well, so that I know that out of the 5 things she has told me, all 5 are true, correct and reliable and so, in my turn, I can tell her 2 things she must do; the issue can be resolved and we can move on."	Mobile phone		verbal+sound	2nd-hand subjective		Y	first-hand laboratory data	misdiagnosis
	30	Communicating on the phone or by text messages carries a risk of misdiagnosis, of wrong assessment due to subjective comments/observations of a person not considered reliable	phone-call/ SMS	written+verbal	verbal+written	2nd-hand subjective	N	Y	-	misdiagnosis